

## **MEETING SUMMARY PRESIDENT'S CANCER PANEL**

### **IMPROVING CANCER CARE FOR ALL: REAL PEOPLE, REAL PROBLEMS WHY DON'T ALL AMERICANS GET THE BEST AVAILABLE CANCER CARE?**

November 16-17, 2000  
Nashville, Tennessee

#### **OVERVIEW**

The President's Cancer Panel was chartered to monitor and evaluate the development and execution of the National Cancer Program (NCP) and to report to the President on barriers to Program implementation. This meeting was the fourth in a series of regional meetings exploring issues that affect the ability of communities to provide cancer care—including prevention, education/communication, detection, treatment, diagnosis, rehabilitation, palliation, and end-of-life care—to people in the diverse neighborhoods of the Nation. This meeting brought together representatives from eight States in the southern United States, as well as Puerto Rico and the U.S. Virgin Islands, to discuss these issues, the barriers faced at local levels, and local- and State-level efforts to address them. The delegations, composed of up to six individuals, included cancer survivors who described their personal experiences both with the disease and in obtaining needed information and treatment.

#### **MEETING PARTICIPANTS**

##### **President's Cancer Panel**

Harold P. Freeman, M.D., Chairman  
Paul Calabresi, M.D. (immediate past member)

##### **National Cancer Institute**

Maureen O. Wilson, Ph.D., Assistant Director, National Cancer Institute (NCI), and Executive Secretary, President's Cancer Panel  
Robert Hiatt, Deputy Director, Division of Cancer Control and Population Sciences, NCI

##### **Speakers**

Daisy Avila, R.N., Oncology Nurse, San Pablo Hospital (Puerto Rico)  
Luis Baez, M.D., VA Medical Center (Puerto Rico)  
Margo Blake, Program Administrator, Florida Department of Health (Florida)  
Gordon Bonnyman, Managing Attorney, Tennessee Justice Center (Tennessee)  
Toni H. Bounds, Ph.D., M.P.H., Program Director, Tennessee Cancer Registry, Tennessee Department of Health (Tennessee)  
Margaret Bowen-Jones, B.S.N., Chairperson, Mississippi National Black Leadership Initiative on Cancer (Mississippi)  
Viki Brant, M.P.A., Director of Cancer Prevention, Alabama Department of Public Health (Alabama)  
Debbie Christopher, Health Educator/Community Activist, Virgin Islands Department of Health (Virgin Islands)  
Sherry Davis, Community Representative (Florida)  
Beverly Diamond, Community Representative (Mississippi)  
Shauna Dominic, M.H.S., Health Disparities Consultant, Office of Minority Health, South Carolina Department of Health (South Carolina)

Loretta Farris, Community Representative (Kentucky)  
 William Fogarty, M.D., Pathologist, Juan F. Luis Hospital and Medical Center (Virgin Islands)  
 Melody Fortune, Director, Breast and Cervical Cancer Program, Mississippi State Department of Health (Mississippi)  
 Mona Fouad, M.D., M.P.H., Associate Professor, University of Alabama (Alabama)  
 Gilbert Friedell, M.D., Director Emeritus, Markey Cancer Control Program (Kentucky)  
 Sam Frost, Community Representative, Best Chance Network (South Carolina)  
 Venus Ginés, Coordinator, Latin Cancer Awareness (Georgia)  
 Lorna Harris, Ph.D., Dean, School of Nursing, A&T State University (North Carolina)  
 Maria Harris, Community Representative (Tennessee)  
 Rosa Hill, Community Representative (Alabama)  
 Joyce Hudson, Outreach Liaison, Best Chance Network (South Carolina)  
 Harry Jacobson, M.D., Vice Chancellor for Health Affairs, Vanderbilt University Medical Center (Tennessee)  
 Angela Y. Johnson, Community Representative (Georgia)  
 David Johnson, M.D., Clinical Director, Vanderbilt-Ingram Cancer Center (Tennessee)  
 Yung Krall, Director, Multi-National Relations, Emory Northlake Regional Medical Center (Georgia)  
 Barbara Kubilus, M.S.W., Director of Health and Fitness, YWCA (Florida)  
 Greg Lawther, M.S., Manager, Chronic Disease Prevention and Control Branch, Kentucky State Department of Health (Kentucky)  
 Marie-Jose Ledan, Community Organizer, Haitian Women of Miami, Inc. (Florida)  
 Nedra Lisovicz, M.P.H., C.H.E.S., CHAN Director, Center for Sustainable Health Outreach (Mississippi)  
 Deirdre Mack, Community Representative (North Carolina)  
 Alvin Mauer, M.D., Professor Emeritus of Medicine, University of Tennessee Health Science Center (Tennessee)  
 John Maupin, D.D.S., President, Meharry Medical College (Tennessee)  
 Clifton Meador, M.D., Executive Director, Meharry-Vanderbilt Alliance (Tennessee)  
 Harold L. Moses, M.D., Director, Vanderbilt-Ingram Cancer Center (Tennessee)  
 Jarrett Mynear, Community Representative (Kentucky)  
 Cruz M. Nazario, M.D., Epidemiologist, University of Puerto Rico (Puerto Rico)  
 Mark O'Rourke, M.D., Private Practice Physician (South Carolina)  
 Deborah Porterfield, M.D., Branch Head, North Carolina Division of Public Health, DHHS (North Carolina)  
 Irene Prabhu Das, M.P.H., Director, Best Chance Network (South Carolina)  
 Deborah Richardson, M.P.A., Program Director, Virgin Islands Central Cancer Registry (Virgin Islands)  
 Carlos Sandoval-Cros, M.D., Director, Courtelis Center for Research and Treatment of Psychosocial Oncology (Florida)  
 Shelby Sanford, M.D., Chief Executive Officer, Southeast Cancer Network, PC (Alabama)  
 Carol Steiner, R.N., M.N., Director, Cancer Control Section, Georgia Department of Human Resources, Division of Public Health (Georgia)  
 Dorothy Straun, Certified Nurse Assistant, Juan F. Luis Hospital and Medical Center (Virgin Islands)  
 Robert Teague, M.S.W., Community Representative (Mississippi)  
 Sr. Eneida Torres, Community Representative (Puerto Rico)  
 Wayne Tuckson, M.D., Colorectal Surgeon, University of Louisville (Kentucky)  
 Keith Wailoo, Ph.D., Professor, Department of Social Medicine and Department of History, University of North Carolina at Chapel Hill (North Carolina)  
 Dranda Whaley, M.P.A., TennCare Consumer Advocacy Program (Tennessee)  
 Joette Whitlow, Community Representative (Alabama)  
 Elizabeth Owle Wiggins, F.N.P., Director, Cherokee Women's Wellness Center (North Carolina)  
 Carolyn Williams, Social Worker, Oncology Clinic, University Hospital (Georgia)  
 Gilbert B. Zimmerman, Community Representative (South Carolina)

**NOVEMBER 16, 2000**

**OPENING REMARKS—DR. HAROLD FREEMAN, CHAIRMAN, PRESIDENT’S  
CANCER PANEL**

- Dr. Freeman welcomed the participants, noting that although Dr. Dennis Slamon and Ms. Frances Visco were unable to attend the meeting, Dr. Paul Calabresi, immediate past member of the Panel, was in attendance as an expert consultant. Dr. Calabresi is one of the driving forces behind the current series of meetings. Dr. Freeman thanked Dr. Calabresi for his 5 years of service on the Panel and presented him with a certificate of appreciation from the National Cancer Institute.

**WELCOME—DR. HARRY JACOBSON, VICE CHANCELLOR, VANDERBILT  
UNIVERSITY MEDICAL SCHOOL**

- The United States has a wealth of health care resources—including medical education, biomedical research capabilities, hospitals and clinics, technologies, and drugs—yet major health care problems exist.
- In addition to the increasing cost of delivering health care, the inconsistency with which health care is delivered to citizens of this country ranks as one of the most significant problems in the field today. A number of factors, including the large number of uninsured, access to care, and the uneven application of prevention and treatment interventions for cancer, contribute to these discrepancies.

**REMARKS—DR. HAROLD MOSES, DIRECTOR, VANDERBILT-INGRAM CANCER  
CENTER**

- Research conducted under the auspices of the National Cancer Program has led to spectacular successes in understanding the basic causes of cancer. Based on this knowledge, we now know how to prevent many cancers, and exciting therapies have been developed that target specific lesions that occur in cancer cells. These new drugs are expected to be far more effective than older therapies in treating cancer, with fewer undesirable side effects. Much of this work has been carried out at NCI-designated Cancer Centers.
- The ultimate goal of preventing most cancers and safely treating those that do develop will not be realized unless everyone in the country has full access to state-of-the-art health care.
- The collaborative partnership of the Meharry Medical College and Vanderbilt-Ingram Cancer Center develops innovative strategies to understand and eliminate racial, economic, and other barriers to care. Under the leadership of Dr. John Maupin, Meharry continues its legacy of training minority physicians and addressing health care needs of the underserved.

**REMARKS—DR. JOHN MAUPIN, PRESIDENT, MEHARRY MEDICAL COLLEGE**

- The partnership between the Vanderbilt-Ingram Cancer Center and Meharry Medical College is an example of uncommon leadership that has reached out across barriers to make life better for Americans regardless of their race, ethnic background, education, or economic status.
- The National Cancer Program must ensure that its successes are enjoyed by all Americans.

**BACKGROUND—DR. HAROLD FREEMAN, CHAIRMAN, PRESIDENT’S CANCER  
PANEL**

To put the current meeting into context, Dr. Freeman indicated that:

- The Panel’s 1999 report to the President of the United States noted the real and substantial progress that has been made against cancer—particularly since 1971—but identified a significant disconnect between research discoveries and the delivery of the benefits of this knowledge to the American public. The report also stressed the importance of recognizing and addressing the barriers that keep quality cancer prevention and care from reaching people in all of the neighborhoods of the Nation. Further, the Panel concluded that the unequal burden of cancer carried by the poor, ethnic minorities, and the underserved must be relieved.
- Additional recommendations in the report included the following:
  - Barriers that prevent the benefits of research from reaching all populations, thus creating health disparities among populations, must be identified and removed.
  - It is the responsibility of legislators and policymakers to enact laws and policies needed to ensure access to quality care for all.
  - Mechanisms are needed to ensure that public and private health care payers have access to and understand evidence for health care interventions and incorporate them appropriately into the standards of care for cancer.
  - Awareness of the cancer problem, as well as current knowledge about prevention and all aspects of care, must be increased through culturally appropriate public and professional education.
  - Public pressure must be brought to bear in recruiting into the national cancer effort sectors that traditionally have not perceived themselves as having a role in solving the cancer problem.
  - The current and future cancer workforce requires greater training in state-of-the-art cancer prevention and care, as well as sensitivity to cultural issues and to the diversity reflected in our population.
- If we do not better connect the research and delivery enterprises, our progress against cancer will continue to be slow, uneven, and incremental. Overcoming the divide between these two components of the cancer effort requires concerted action by all stakeholders. This, the Panel believes, is not just a scientific and medical issue, but a moral and ethical challenge for the Nation.
- All segments of the public must benefit from the discoveries made through the National Cancer Program.

**REMARKS—DR. RUTH KIRSCHSTEIN, ACTING DIRECTOR, NATIONAL INSTITUTES OF HEALTH [VIDEO]**

- The burden of disease, particularly cancer, is not borne equally by all populations. For example, men are approximately 50 percent more likely to die from cancer than women. Among women, Alaskan women are 30 percent more likely than women of other ethnicities to die from cancer. The death rate from prostate cancer in African-American men is twice that of white men. Stomach cancer is substantially more prevalent among Asian/Pacific Islanders—including Native Hawaiians—than among other populations. The incidence of cervical cancer in Hispanic women has been consistently higher at all ages than in other women, although African-American women have the highest mortality rate from this disease. In general, persons of low socioeconomic status have higher cancer death rates than do persons of higher socioeconomic status.
- The causes of these health disparities are multiple and complex; they include, but are not limited to, poverty, inadequate access to health care, lack of health insurance, societal discrimination, lack of education, fear, and incomplete knowledge about cancer treatment, causes, and prevention. In the last

year, several important studies have been published showing that, without question, serious inequities exist in the delivery of health care in this country and that these inequities affect the lives of individuals and certain groups of people.

- NIH and the NCI cannot repair all of the flaws in the health care system, but they do have an important role in combating existing health disparities in cancer and other diseases. Research has an important role in addressing disparities in cancer (especially those related to breast and prostate cancer) and those involving diabetes, infant mortality, AIDS, cardiovascular disease, hypertension, and other diseases. Though strides have been made in some of these areas, they have been insufficient.
- The NIH mission to improve the health of all citizens is an ongoing challenge. We cannot rest until health disparities no longer exist. A new approach to addressing health disparities is needed, and each NIH Institute has developed a strategic plan to address disparities. In addition, the NIH overall strategic plan concentrates work in three areas: additional research, teaching scientists about closing health gaps, and increasing community outreach to disseminate research findings to the people and the health care arena.
- The law establishing the National Center of Minority Health and Health Disparities at NIH, recently passed by Congress and pending Presidential signature, empowers the Center with independent grantmaking authority and provides a welcome structure and focus for research-related activities to address disparities.
- Clinical trials remain the only means of integrating new treatments, prevention strategies, and diagnostic advances into medical practice and applying research achievements to patients. Treatment of children with cancer has been remarkably successful because, for years, the majority of these children has been treated in clinical trials or has received treatments that had been tested in clinical trials.
- By contrast, approximately 3 percent of adults with cancer participate in clinical trials. Changes in Medicare benefits, which now cover regular clinical care costs for patients in clinical trials, should increase and broaden adult cancer patient participation in trials.
- The NIH will fully support the work of the NCI to improve the care and treatment of cancer patients through research—particularly in efforts to reduce and eliminate health disparities.

## **DIRECTOR'S REPORT—DR. ROBERT HIATT, DEPUTY DIRECTOR, DIVISION OF CANCER CONTROL AND POPULATION SCIENCES, NATIONAL CANCER INSTITUTE**

Representing Dr. Richard Klausner, Director, NCI, Dr. Hiatt indicated that:

- Contemporary cancer control, broadly defined as “the useful application of results from cancer research to practice,” is a refinement of the phrase “the useful application of results,” originally contained in the 1937 National Cancer Act.
- Contemporary cancer control starts with fundamental research, the foundation for intervention and intervention research. The sound basis of evidence derived from fundamental research informs the actions of clinical and community practitioners. Surveillance research measures current health status and enables us to determine the impact of interventions. Progress against observed health disparities is dependent upon effectively synthesizing and applying surveillance information to guide clinical application.

- NCI's purview encompasses the full spectrum of cancer causes and intervention, including physiologic, genetic, and basic sciences, and more recently, behavioral and sociocultural effects on health care outcomes.
- Progress to date has been astounding. Both cancer incidence and mortality are decreasing—incidence has decreased 1.3 percent per year in the latter part of the last decade, and mortality decreases accelerated over the same period. In addition, there now are more than 8.4 million cancer survivors. Despite these successes, unacceptable health disparities and quality-of-care variations still exist.
- As stated in the 2002 NCI Bypass Budget, and as indicated by increased requested budget commitment, NCI's new areas of emphasis—surveillance, quality of care, and health disparities—reflect identified research areas in which it is believed the time is ripe to make substantial progress.
- The goals for health disparities lie in understanding the causes of health disparities in cancer and developing effective interventions.
- Quality-of-care variations exist even with excellent cancer care in this country. To achieve the goal of identifying and mitigating variations in quality requires enhancing the state of science in defining, monitoring, and improving quality of cancer care as well as informing Federal-level decisionmaking on cancer care delivery, coverage, and regulation.
- Within the overall structure of the research enterprise, four principal goals have been identified to strengthen NCI's cancer surveillance program:
  - First, NCI will improve cancer surveillance by expanding the Surveillance, Epidemiology, and End Results (SEER) program to include other States and populations. Although SEER provides the highest-quality cancer registry data, it does not yet adequately represent all major population groups nationwide. In addition, the types of data collected on all populations will be broadened and will include links to data on quality of life, risk factors, screening, patterns of care, and even the collection of biologic samples.
  - Second, systems and methods to improve data quality will be expanded. Data quality is critical to ensure that collected data provide correct answers to research questions and enable investigators to generate hypotheses. Further, surveillance data enable researchers to assess “where we are” in terms of the cancer burden and inform the research enterprise.
  - Third, NCI will expand surveillance research training, not only in areas such as registration and statistics, but in areas such as geography, health behavior, and health services research.
  - Lastly, to achieve nationwide coverage with good surveillance data, NCI and the Centers for Disease Control and Prevention (CDC) are collaborating to launch an integrated national surveillance program.
- NCI has identified five areas of importance in health disparities, beginning with fundamental research. This research is needed to understand the root causes of health care disparities. From this basis of understanding, intervention research next determines how best to attack the causes and to effect change. Infrastructure is needed to support a major focus on health disparities through centers and other structures. Training that brings together multiple disciplines (e.g., epidemiology, clinical medicine, sociology, anthropology, political science) is critical to understanding issues related to disparities. Lastly, the NCI Center to Reduce Cancer Health Disparities, led by Dr. Freeman, provides a critical and much-appreciated opportunity to achieve progress in these areas.
- In addition to the Center to Reduce Cancer Health Disparities, NCI's new focus includes three other initiatives in the area of health disparities. First, activities are underway to support Centers for Population Health, which will bring together population scientists to attack problems involving health

disparities and social determinants. Second, Special Population Networks (SPNs) work with communities to assess their needs for cancer information and cancer action. These networks also engage the research enterprise to address identified needs and reduce disparities. Finally, a systematic, focused effort is being undertaken to assess the problems associated with information dissemination and diffusion.

- Three key objectives have been identified in the area of quality-of-care research. First, core processes and endpoints yielding consistent measures of cancer outcomes and quality treatment must be developed. These processes and endpoints must provide knowledge as to the progress or efforts that are occurring nationwide. Second, strengthening the methodological base will make it possible to understand the relationship among cancer treatments, cancer interventions in the community, and agreed-upon outcomes. Third, NCI's restructuring of the entire clinical trials program has resulted in an optimal infrastructure upon which to better understand not only quality measures and patient-centered measures, but also what people value in terms of cancer treatment. These values involve not just cancer survival, but issues of, for example, quality of life, functional performance, and impact on family.
- Good communications are an integral component of quality care. Cancer communications span a broad spectrum from the doctor-patient interaction through interactions occurring via new information technologies such as the Internet and the World Wide Web, as well as the cultural tailoring of messages.
- NCI's efforts in quality of care have been motivated by four factors: the extensive history of patterns-of-care studies focusing on in-depth problems within the surveillance system; the Surveillance Implementation Report that reviews NCI surveillance activities; the President's Cancer Panel report (issued January 1999) on quality of life and quality of care; and the National Cancer Policy Board's report on ensuring quality cancer care.
- The National Cancer Policy Board report contains 12 recommendations that focus attention on critical national issues in assessing quality of care and has resulted in several initiatives. One of these is the Cancer Care Outcomes Research Surveillance Project (CANCORS), a large Request for Applications (RFA). CANCORS' focus is to study the impact of targeted interventions on patient-centered outcomes and to investigate the dissemination of state-of-the-art therapies in the community by examining modifiable risk factors and analyzing disparities in the quality of cancer care. CANCORS will be a 5-year, \$340 million prospective cohort study involving approximately 6,000 cancer cases.
- CANCORS will study socioeconomically diverse patients treated in a full range of settings. Five to seven research teams will be deployed per cancer site, focusing initially on colorectal cancer and lung cancer. Teams will examine core data sources and records: surveys of patients, physicians, and claims data. In addition, teams will track dissemination of new technologies and support special research projects. CANCORS' broad scope will advance understanding of quality measures, demonstrate their impact on agreed-upon outcomes, and facilitate understanding of variations in care across settings in geographic areas as well as the differences measured by health disparities.
- The NCI enlisted the cooperation of diverse Federal agencies and groups to participate in the Institute's broad initiative on improving the quality of cancer care through the Quality of Cancer Care Committee (QCCC). QCCC's membership includes the Agency for Healthcare Research and Quality (AHRQ), the Health Care Financing Administration (HCFA), CDC, the Food and Drug Administration (FDA), the Health Resources and Services Administration (HRSA), the Indian Health Service (IHS), other Department of Health and Human Service (DHHS) agencies, the Veterans Administration (VA), and the Department of Defense (DoD). QCCC will focus broadly on quality-of-care problems, with a particular emphasis on the translation of research discoveries into application and delivery.

## TENNESSEE

### Presenters

**Dr. Toni Bounds**

**Mr. Gordon Bonnyman**

**Dr. Alvin Mauer**

**Ms. Dranda Whaley**

**Ms. Maria Harris**

### DR. TONI BOUNDS

#### Key Points

- Three interrelated barriers hinder efforts to provide proven cancer prevention and control interventions to people with cancer and those most at risk throughout Tennessee. First, Tennessee has no mechanism in place to provide intervention programs for cancer prevention and control. Second, Tennessee has three diverse cultural, racial, and ethnic regions that include minority and underserved pockets within specific geographic areas. Third, Tennessee lacks a strong population-based cancer registry to provide the mechanism to measure the impact of intervention programs.
- Though community-level local prevention and control programs exist, Tennessee lacks an evidence-based, statewide, unified cancer prevention and control program. A statewide effort is needed that identifies and localizes cancer problems and provides a mechanism by which to measure outcomes at the local level.
- Sufficient infrastructure exists to unify and strengthen local community programs and enlist the support of dedicated professionals at the local level. All 95 counties in Tennessee have health councils comprising citizens who define local health problems. Tennessee also is divided into 13 health regions; each of these has a health council that addresses regional health care needs.
- Each of Tennessee's three diverse geographic regions—East, Middle, and West—possesses distinct and unique minority and underserved areas, or “population pockets.” These pockets require tailored approaches to cancer prevention and control. East Tennessee is principally an Appalachian culture; Middle Tennessee is a Southern culture with considerable in-migration due to the music industry in the area; West Tennessee is a Deep South farming culture.
- Of Tennessee's approximately 5.5 million residents, 83 percent are white, 16 percent are African-American, and the remaining 1 percent comprises all other races and ethnicities. Approximately 72 percent of African Americans live in eight counties divided between two pockets in Middle and West Tennessee. Ten counties in the East region and the eastern side of the Middle region have fewer than ten African-American residents per county; three counties have no African-American residents. East Tennessee has a significant underserved population of poor white Appalachians. Few data exist on the areas of residence of Tennessee's Hispanic population or on how to reach that population.
- Tennessee needs to transition its existing cancer surveillance system to a centralized, population-based system that will provide a complete picture of disease distribution in the State. Cancer has been a reportable disease in Tennessee since 1983, but only hospitals have been required to report. In 1997, Tennessee received funding from the CDC through the National Program of Cancer Registries, but it was one of the last States to join, and it continues to struggle to comply with national standards. The Tennessee legislature recently passed an amendment that will make it possible to launch a population-based system and continue to receive Federal funding. Tennessee will require additional guidance and support to enable meaningful measurement of intervention programs.



## **Recommendations**

- The President and Congress could help Tennessee overcome its barriers to proven intervention for cancer prevention and control, which involves four key initiatives:
  - Establish guidelines and standards for cancer prevention and control programs.
  - Facilitate mentoring and networking activities with States that currently have ongoing prevention and control programs. Such interaction would enable Tennessee to get guidance and support for its program.
  - Provide guidance in creating specific intervention programs for Tennessee's cultural and minority population pockets.
  - Increase Registry funding to provide additional resources to support statewide cancer prevention and control programs.

## **MR. GORDON BONNYMAN**

### **Key Points**

- Economic and racial barriers to appropriate treatment for catastrophic diseases such as cancer are closely interrelated. Few people can afford to meet the expenses of cancer without insurance, but 42.6 million Americans are currently uninsured, and an estimated equal number are underinsured (i.e., insurance coverage is inadequate to afford them assured access to essential health services). Whether one is underinsured depends upon the seriousness of medical need: The greater the need, the greater the impact of an illness, and the more comprehensive one's insurance must be.
- The United States is the only industrialized nation besides South Africa that operates a market-based health insurance system that makes no provision for universal health insurance coverage. This combination of characteristics creates a major barrier to access to essential care—for both people with cancer and people with any other disease—and directly and negatively affects survival and quality of life. Uninsured and underinsured patients routinely are denied the cancer care needed to save their lives. Most people know the importance of treating cancer at an early stage to improve the chance of survival. For the uninsured and underinsured, the terror of having no access to care for diagnosed cancer is a quality-of-life issue as well as a survival issue. In addition, some patients are denied pain medication due to lack of insurance. Patients on fixed incomes (e.g., Social Security pensions) often cannot afford to fill their prescriptions for cancer drugs.

### **Recommendations**

- Be intellectually honest and recognize that a market-based health care model results inevitably in people without the means to pay—and who will thus not receive good care. More research is needed about the sources of these economic barriers, but much of the problem is abundantly clear.
- Acknowledge that the current health care system is based not on rationing absolute scarcity but on rationing surplus. We have adequate capacity—and in some sectors we have overcapacity—yet, based on ability to pay, it is not available.
- Stop blaming victims. Most victims' fatalism derives from lifetimes of experience that has shown that there is no point in getting screening if treatment is not affordable.

- Ensure access to care across the board and ensure that care is adequate to the need. Having cancer does not result in an exemption from other medical needs, and cancer does not observe the kind of convenient boundaries that public programs tend to create.
- Elevate the consciousness of providers to the shortcomings of the system. Providers need to be sensitive to financial barriers and understand that these barriers prevent some patients from obtaining prescribed items. Providers need not denigrate or demean patients as noncompliant, but should realize that fulfilling the prescribed order is financially impossible.
- Collect data on racial and ethnic identifiers in the health care system. These data are needed to support research on disparities. Although much is known about the correlation between race and poverty, and race and lack of insurance, other factors and contributors continue to sustain significant racial disparities in care.
- Conduct more research on the outcome impact of State-level efforts such as Tennessee's TennCare Program in providing comprehensive coverage across disease boundaries to people who previously were uninsured or underinsured.

## **DR. ALVIN MAUER**

### **Key Points**

- A survey conducted during the mid- to late 1980s comparing Cancer Registry data on the extent of cervical and breast cancers among patients from the regional medical center and those from the Methodist Hospital (a typical private hospital) produced two significant findings. First, compared with patients at the private hospital, approximately one-third fewer women coming to the regional medical center presented with curable disease. Second, compared with those at the Methodist Hospital, over twice the number of women coming to the regional medical center had distant metastases. Followup interviews with medical center patients determined that these differences were not due to lack of information about cancer or to access problems once a person decided to enter the health care system. Poverty, however, was identified as a possible factor contributing to observed differences. The proportion of the Memphis population living in poverty is approximately 20 percent, the highest of the southern cities used for comparison.
- Since the time the survey was conducted, Tennessee launched the TennCare program, which replaced Medicaid in the State. Under TennCare, the poor receive care under a capitated arrangement with 12 health maintenance organizations (HMOs) in the State. The State also launched a Breast and Cervical Cancer Early Detection Program (BCCEDP). Both programs provide access to early detection for breast and cervical cancer.
- To determine if TennCare is making a difference in mammography utilization, a cohort of 300 women aged 50 to 65 was studied, both before and after TennCare. In the 2 years prior to TennCare's implementation, approximately 8.9 percent of the cohort had mammograms in 1991, and 14.2 percent had mammograms in 1992. After TennCare implementation, mammography utilization had climbed to approximately 20 percent in 1995 and 25 percent in 1996. Despite this improvement, further study is needed to determine why many women in the target group still are not receiving mammograms.
- In the BCCEDP, mammography utilization is relatively good, but the Program does not cover women older than 64. Women 65 and older should receive mammograms through Medicare. However, the mammography rate for women 65 and older decreases significantly—almost to zero. Recent discussions with relatively affluent, educated older women suggest that a major problem is the belief among older women that mammograms are no longer needed. Increased recruitment efforts are needed in the over-65 population.

- The African-American population in Memphis, which is in the majority, appears to be seriously underserved by the BCCEDP. Over 80 percent of women having mammography screenings have been Caucasian; by contrast, African-American women represent only 14 percent of the total. Hispanics are likewise underrepresented. Outreach will be the key to improving these statistics.

## **MS. DRANDA WHALEY**

### **Background**

The TennCare Consumer Advocacy Program, a service of the Crisis Intervention Center, advocates for TennCare participants and those eligible for TennCare whose medical needs are either not addressed or are unresolved. More than 15,000 cases have been opened since 1994. The Advocacy Program assists enrollees and eligible individuals by working with the TennCare Bureau, the managed care organization (MCO), or the doctor or other provider to resolve virtually any problem. The Program also has handled more than 190,000 information and referral calls that did not result in open cases.

### **Key Points**

- Data are collected on the medical problems of individuals who call the Program for assistance. Cancer is the second most common problem among callers.
- To determine whether or not to open a case, Program workers determine: 1) the problem, and 2) with whom it will be necessary to work to resolve the problem—i.e., the enrollee, the managed care organization, or the TennCare Bureau. Of the callers in 2000 with cancer (to date), 61 percent of the open cases required working directly with the enrollee either to obtain enrollment or to resolve a problem with enrollment. In 17 percent of cases, it was necessary to work with the TennCare Bureau. Typical case problems include computer errors and processing delays, often regarding the initial application; dissatisfaction with care received from the caller's MCO; or effective-date problems—i.e., application and paperwork were submitted but delays were created due to paperwork errors.
- Other common problems include issues concerning medications not on the MCO's formulary, access to specialists recommended by the primary care provider but not included in the MCO's network, and provider barriers such as getting approval for medications, services, and durable medical equipment.
- Overall, 66 percent of cases closed with a successful resolution. Twenty-five percent of the cases closed with a pending resolution requiring further monitoring to ensure that the anticipated action occurred. In 3 percent of cases, resolution was unsuccessful; in another 3 percent of cases, contact with the enrollee was lost before the case could be closed.

## **MS. MARIA HARRIS**

### **Background**

Shortly after her 44<sup>th</sup> birthday in 1996, Ms. Harris discovered a lump in her breast during a self-examination. She was diagnosed with stage II carcinoma, and over a 14-month period, she underwent a right radical mastectomy, 16 weeks of chemotherapy, a bone marrow transplant, 36 radiation treatments, and 4 reconstruction surgeries. After completing her 14-month treatment, and 3 weeks after she spoke with her employer about returning to work, Ms. Harris was fired on the basis of her long-term illness. She has since become involved in community cancer screening efforts.

## **Key Points**

- Increased awareness, education, research, and early detection efforts are needed to combat cancer.
- Employers should be more compassionate and understand that people with cancer need time to recover in order to return to work as whole people. The duration of this absence from work should be determined by the patient, not the employer.
- The American Cancer Society (ACS) and other community-based businesses and organizations should become more involved in cancer screening.

## **DISCUSSION—STATE OF TENNESSEE**

### **Key Points**

- Tennessee does not currently have a State Cancer Plan; such a plan is needed. The Department of Health recently established an Office of Cancer Surveillance. It is hoped that a plan will be developed through that organizational locus.
- Many other countries have market-based systems with private provision of care yet still have universal coverage because public policy provides for such coverage. No country has a pure market for health care; all elements of a pure market would be difficult to replicate in the health care system—for example, consumers lack perfect knowledge, and competition is constrained by barriers to entry into markets. Yet most Western industrialized countries have private provision of services with what are essentially quasi-markets. Private insurers in those countries operate in a market-type environment but still provide universal coverage. Market-based systems and universal coverage are not inherently incompatible. Such a public/private mix is the model in industrialized countries other than those from the former Soviet bloc. It is somewhat disingenuous to say that we cannot understand why people without the means to pay do not get care in a strictly market-based or quasi-market-based system. Public policy must address the inevitable gaps in coverage that occur in a market system. The commercial insurance system cannot work for many people with low incomes or costly medical conditions.
- Under TennCare, women with positive mammograms have care available to them through their MCOs. Under the Tennessee BCCEDP, however, a person with diagnosed cancer must go through the process of being denied insurance to become eligible for TennCare; that process can take up to 6 months. The State is working to make TennCare eligibility automatic in cases of documented breast cancer.
- Recent passage of the National Breast and Cervical Cancer Treatment Act may make it easier for women diagnosed with these diseases under CDC screening programs to obtain timely treatment.
- Although TennCare has its shortcomings, it does represent progress that any State in the Nation can make to provide access for a greater number of its citizens. It shows that we can do better as a nation. Having so many uninsured people is not a natural condition imposed upon us as an “act of God.”
- There still exist in Tennessee a considerable number of people (approximately 8 percent of the adult population) who are uninsured, have no access to health care, and cannot enroll in TennCare at this time. Prior to TennCare, however, the uninsured rate among adults in the State was approximately 13 percent.

## **PUERTO RICO**

### **Presenters**

**Dr. Cruz M. Nazario**

**Ms. Daisy Avila**

**Sister Eneida Torres**

**Dr. Luis Baez**

## **DR. CRUZ M. NAZARIO**

### **Background**

The population of Puerto Rico numbers approximately 4 million; it is considered a Hispanic population that is undergoing dramatic social changes. In the past 50 years, Puerto Rico has changed from a rural agricultural society to a highly urban and densely populated one. Infectious diseases—with the exception of AIDS—have given way to chronic ailments.

Puerto Rico is actually an archipelago of many islands that is well characterized in terms of its sociodemographic factors. Since 1950, Puerto Rico has had a population-based Central Cancer Registry that collects information from all cancer patients diagnosed, treated, and followed in the islands. It collects clinical information, treatment modalities, and patient status among other data. However, the last population-based cancer report was published in 1993, using 1991 data. It is likely that these hospital-based data have been strongly modified by more recent referral and economic patterns, which impair the use of such information for the whole population. Thus, there are no recent population-based cancer data for the large Hispanic population of Puerto Rico.

### **Key Points**

- Even NCI reports lack cancer data on Hispanics that is comprehensive, comparable, or sufficient to be helpful in explaining risk patterns and epidemiologic differences. These data are important in designing and implementing cancer prevention and control programs and in understanding the survival disparities among different ethnic groups in America—even after correcting for stage of disease at diagnosis. NCI's 1992 report had no information on Hispanics, although the previous report had good, though limited, information on Hispanics in New Mexico and Puerto Rico. In NCI's most recent report (1996), Hispanics were included, but Puerto Ricans were excluded. Other NCI reports included data on Hispanics, but these data are not comparable, since Hispanic populations were defined differently.
- Limited cancer data create a major barrier to providing better health care for Puerto Ricans. The Cancer Registry could provide such data, but changes in Puerto Rico's Health Department have impaired this valuable resource.
- Cancer patients on the more remote islands of Puerto Rico must take ferries and other public transportation to access treatment. Such trips can take hours each way. After receiving chemotherapy, patients must make the same trip home; a patient who misses the last ferry will likely have to sleep in the public square. Though poor patients can qualify for catastrophic funds to cover their treatment, there is no provision for transportation or lodging.
- Many women in remote areas of Puerto Rico have never had a Pap smear or mammogram. In particular, it is suspected that managed care gatekeepers in the health care system limit access to diagnostic procedures, thus postponing early treatment. Even if patients qualify for catastrophic funds to pay for treatment, they must first be diagnosed.

- A study in Puerto Rico suggested that brain tumors have decreased since 1994, when health reform was implemented. No etiological explanation for this observation has been provided; thus, this finding likely is due to increased use of magnetic resonance imaging (MRI) and computed tomography (CT) to diagnose patients insured by MCOs.
- Lack of current cancer data prevents epidemiologic evaluation of the effects of screening and early treatment on mortality trends in Hispanics.
- Research results may not be reaching the community, in part, because some of the research questions are not addressing the needs of minorities. NIH had to force many researchers to include minorities in their research projects; some researchers had claimed that minorities were not reliable or compliant, even though there are no data to support such statements.
- Applying research results based on studies in populations with different risk patterns from specific populations can lead to significantly incorrect assumptions and results. For example, lifetime breast cancer risk for Hispanic women, if estimated using incidence and mortality data from either white or African-American women, will be greatly overestimated.
- A study was conducted using data specific to Hispanics in Puerto Rico as well as SEER data for African-American and white females. Using comparable 1985-1989 data, lifetime risk for breast cancer is about 13 percent for white U.S. females, 8.8 percent for African-American women, and 5.4 percent for Puerto Rican Hispanics. Even though Hispanics have lower risk and possible protective factors, breast cancer rates are increasing among Hispanics four times faster than among white women in the United States and do not appear to have leveled off. Breast cancer incidence is still increasing, and mortality is not decreasing among women in Puerto Rico.

## **Recommendations**

- Cancer information on Hispanics that is population-based, reliable, comparable, and systematically collected is urgently needed.
- Appropriate research questions that help uncover barriers to cancer treatment or preventive services in minority populations must be designed and implemented without delay.

## **MS. DAISY AVILA**

### **Key Points**

- As an oncology nurse in Puerto Rico for 7 years, Ms. Avila has seen cancer patients lose their jobs and become dependent when they had been independent. Many were the family breadwinners—particularly divorced mothers with dependent children. In addition, elderly cancer patients tend to be marginalized, with families living far away. Many are in nursing homes.
- Cancer patients who have lost their jobs often cannot get private medical coverage. Medicare covers 80 percent of expenses, but Puerto Rico has among the lowest Medicare payment rates. Annual premiums of \$100 and the \$776 hospital deductible are unaffordable for patients whose only income is Social Security and other Government assistance. Another plan requires patients to pay 40 percent of chemotherapy service costs and covers only 12 treatments per year. Radiotherapy is not covered, nor are psychiatric services. Such plans are inaccessible for most patients.
- At the oncology center at which Ms. Avila works, radiotherapy is not available; patients must travel 2 hours to receive radiation treatment. Sometimes, chemotherapy and radiotherapy are given on the same day, increasing the likelihood and severity of nausea and vomiting.

- The government of Puerto Rico has privatized health services for the medically indigent, but the private plans do not cover equipment, home services, or ambulances. Patients cannot access specialists unless they are referred.
- Many physicians lack education about cancer and try to treat patients with cancer as they would those with routine illnesses. By the time many patients reach the oncology center, they have advanced disease. Referral to specialty care is delayed because of capitation arrangements under the privatized health system for indigents. In Puerto Rico, the Health Department's mobile mammography unit travels to various towns to provide mammography, but only the first ten patients are accepted, and they must be privately insured.
- Health plan fees are very low, and physicians often wait 6 months for payment. No law requires the medical plans to pay within the time stipulated in the contract with the physician; thus, there are contracts, but no payments.
- Other needs include: greater education and training for cancer care personnel; a computerized cancer database with a national network to enable care to be coordinated by cancer type and stage with consideration of age, mobility, and need for multidisciplinary care; and cancer information in Spanish.
- The oncology center at Aibonito has been successful in referring leukemia patients to NIH for bone marrow transplants.

## **SISTER ENEIDA TORRES**

### **Background**

Sr. Eneida Torres is a cancer survivor and member of a support group in Aibonito, Puerto Rico, providing emotional and spiritual services to cancer patients.

### **Key Points**

- Some patients do not receive care because they lack transportation. One such case is a couple who both have cancer; they have small children to care for and no means of getting to treatment.
- The support group is assisting a woman with terminal cancer who is caring for her 100-year-old mother and a 4-year-old boy. Significant emotional support is needed through social workers and mental health professionals to manage the crisis that is the result of her illness.
- Cancer information in Spanish is badly needed; most patients cannot understand information presented in English.
- Patients also need nutritional assistance and access to services and equipment such as positionable beds, wheelchairs, scales, and prostheses. Only Medicare provides any of these, and only on a limited basis.
- Access to preventive medicine is poor. Cancer patients who have been treated by general physicians present at the oncology center with terminal disease.
- Other needs include ambulatory chemotherapy; spiritual and emotional support; education for nursing and volunteer staff; and help in obtaining services for patients' basic needs, including clothing, food, shelter, and monetary support.
- On the positive side, events have been held to support patients and their relatives. These include opportunities for patients to share their experiences, supportive workshops for relatives, workshops for professionals to help them cope with spiritual and emotional fatigue, educational workshops for

children, and musical support and spiritual reflection. Other activities include a Christmas tree for patients, an upcoming quarterly newspaper, and a celebration of friendship.

- [a video was shown]

## **DR. LUIS BAEZ**

### **Background**

The San Juan Minority-based Community Clinical Oncology Program (CCOP), Veterans Administration Hospital, City Hospital, Oncologic Hospital, Bayamon University Hospital, Puerto Rico Gastrointestinal Institute, and certain private oncology offices together see close to one-third of treatable cancers on the island. The San Juan CCOP is affiliated with the University of Michigan Cancer Center and a variety of NCI-funded oncology groups and cancer centers. It also conducts pharmaceutical industry-funded trials.

Twenty-four percent of Hispanic Americans are Puerto Rican. Out of this population of about 6.2 million, 56 percent live in Puerto Rico and refer to themselves as Islanders. The population projection for 2000 is 3.9 million. Among this population, 8,886 new cancer cases are expected. Of the Puerto Ricans living on the U.S. mainland, 68 percent live in the Northeast. Since 1917, all Puerto Ricans have been U.S. citizens. Median annual income among Hispanics is about \$23,000, compared with more than \$35,000 for non-Hispanics.

### **Key Points**

- Barriers to implementing new cancer care technologies in the community can be divided into three categories: physician-based, patient-based, and barriers related to the health care environment. An important physician-based barrier is that most physicians on the island are solo practitioners. This practice arrangement may prevent many from traveling to receive continuing education or to participate in professional meetings on the island. In addition, there are additional requirements for membership in mainland professional societies for island oncologists that are not asked of mainland practitioners, decreasing opportunities to gain expertise and maintain proficiency.
- In addition, most physicians have exceedingly busy practices—both by choice and by necessity. Many choose to see a high volume of patients to boost their incomes. At the same time, because Medicare and other health plan reimbursements are so low, many physicians are forced to see 50 to 70 patients a day to obtain a reasonable income. This high patient volume impacts the quality of care these physicians can deliver.
- Patient-based barriers include the high number of single-parent families. As the sole support of their children, patients in these situations often drop out of clinical trials since they cannot risk losing their jobs because of time taken off from work due to treatment side effects.
- Lack of education is among the most important patient-based barrier—less than 15 percent of the population earns a college degree. Without a reasonable education, one cannot prioritize and thereby manage life in a healthy and reasonable manner.
- The health care environment in Puerto Rico poses a significant challenge. It began a major change 8 years ago. That change, creating an HMO-based Medicaid system for the whole island (similar to TennCare), has recently been completed. With this change, the government went out of the business of direct delivery of health care, and funds now flow instead to the contracted providers rather than to institutions owned by the Commonwealth. However, the system is now likely to undergo another major change because of the newly elected island government.



- In the past 3 years, pharmaceutical companies that produce estrogen replacement therapies have been conducting symposia for physicians, attempting to take the focus off tamoxifen as a chemopreventive agent in breast cancer.

## **DISCUSSION—PUERTO RICO**

### **Key Points**

- Cancer rates for Hispanics and the U.S. population overall are similar, but in Puerto Rico, lung cancer rates among women is much lower than the U.S. average for women. The most common cancers for men and women are similar to those for the U.S. population. However, the most current data on the population in Puerto Rico are 10 years old; it is likely that some epidemiologic patterns have emerged since then. It has been difficult to compare cancer rates of Puerto Ricans living on the island with those of Puerto Ricans living in the United States since many State cancer registries do not collect data on ethnicity. Most migrating Puerto Ricans retain their cultural and dietary practices, so lower cancer rates that appear to be related to culture and dietary factors are probably still lower among those living on the mainland.
- Pharmaceutical companies and professional societies often hold meetings in Puerto Rico or in the Virgin Islands in the winter. Physicians in Puerto Rico have access to some of these meetings. While continuing professional education is important, the greater problem in Puerto Rico is the health care delivery system itself.
- Accrual rates to clinical trials in Puerto Rico are similar to those elsewhere in the United States, but the treating institutions are small relative to U.S. cancer centers, are minority institutions treating minority patients, and have little research staffing. It has been crucial to try to ensure that patients enrolled in trials will be fully compliant with the treatment regimen, since with smaller numbers of patients, the risk of not being able to complete a study is greater when patients drop out or are noncompliant.
- It is known that there is substantial two-way migration between Puerto Rico and the northeastern U.S., and that some islander Puerto Ricans travel to the United States for cancer treatment and then return home. These patients are usually from the highly educated, completely insured, and economically stable segment of the population; the majority of the population does not travel for treatment. It is not known how migration and treatment patterns have affected cancer survival rates, since the most current survival data are from 1985. A data-sharing agreement among the New York, Connecticut, and Puerto Rican cancer registries existed until 1993, but no such activities are currently ongoing.
- Pharmaceutical companies receive tax shelters for conducting manufacturing operations in Puerto Rico; in exchange, they are required to invest in the island through jobs and donations to hospitals and other organizations. To date, however, no efforts have been made to engage them more directly in cancer control activities that could reduce the cancer burden in Puerto Rico.
- No formal evaluation has been conducted on the impact of the Medicaid HMO system in Puerto Rico. Dr. Baez and colleagues have submitted an application for a grant to conduct such a study. To date, available information on patient outcomes has been withheld from stakeholder organizations. None of the anecdotal evidence suggests that the HMO-based system has had a positive impact on cancer care or outcomes among the target population; cancer patients are still being treated by primary care physicians and referred to specialty care only at very late stages of their disease. In an attempt to address the situation, the San Juan CCOP has offered its services to the largest of the HMO groups to be its oncology gatekeeper. It is hoped that within a year or two, initiatives to improve oncology care will be developed. Initiatives will span the continuum from prevention through followup. In the area of followup, such an initiative is particularly needed, since the managed care system requires that

clinical trial patients return to the primary care provider for followup. It is critical both to patient care and to the success of the trials that the primary care physician conduct followup in accordance with the study protocol.

- Suspected survival disparities among Puerto Ricans are likely due to late treatment, but the greatest delay affecting survival may be in receiving the diagnosis.
- Puerto Ricans generally refer to themselves as Hispanic only after they come to the mainland U.S. Puerto Ricans share cultural similarities and cancer patterns with other Hispanics in the United States. Much more study of Hispanics is needed to identify strong, consistent patterns that will help in understanding cancer risk in this population. Then, additional study by socioeconomic or geographic subgroups is needed to help design cancer prevention and control strategies. A few studies have been conducted to discern differences related to country of origin. Though questions and vocabulary had to be tailored to the various populations, the study data were comparable and proved useful.

## **FLORIDA**

### **Presenters**

**Ms. Margo Blake**

**Dr. Carlos Sandoval-Cros**

**Ms. Barbara Kubilus**

**Ms. Marie-Jose Ledan**

**Ms. Sherry Davis**

### **MS. MARGO BLAKE**

#### **Background**

Almost a quarter of all deaths in Florida in 1999 were due to cancer. The unadjusted crude rates for breast cancer in Florida are among the highest in the country, probably due to the large number of older women who live in the State. In fact, because of its unique, large population of older people, cancer rates for cervical, prostate, colorectal, and all cancer sites combined are among the highest in the Nation.

Florida also has one of the highest immigration rates in the country; this is an especially important issue for cancer control in that the State has a very diverse population in terms of age, race, ethnicity, and income. These immigrants come from all over the world; language and cultural barriers affect access to care.

State revenue comes largely from property and sales taxes; there is no income tax. As a result, funds for services are limited, particularly in the poorer counties. Voters and policymakers often consider such services as cancer screening a secondary priority.

An estimated 2.6 million Floridians, or one in five people under age 65, are uninsured. Sixty-four percent of uninsured Floridians have incomes below \$25,000 a year.

#### **Key Points**

- Lack of insurance and underinsurance due to managed care restrictions are the principal financial barriers to cancer care. Those without insurance are likely to forgo cancer screening, choosing instead to apply scarce resources to food, clothing, shelter, or medications for other family members or loved ones. For the same reasons, these populations delay seeking care for suspicious symptoms, particularly if no monetary assistance is available. Many have untreatable disease when they finally seek care.

- Florida has experienced a major shift from fee-for-service (FFS) to managed care, which has had a mixed impact on access to cancer care. Managed care emphasizes prevention and early detection, but questions are being raised concerning limited choice of quality facilities, timeliness of referrals, limited access to specialists, lack of coverage for certain procedures, unavailability of services in some communities, and restrictions on physicians that limit their ability to provide information about treatment options not covered by “the Plan.”
- The Medicare population in Florida is large. Transportation is a major barrier to care for the elderly. Some locations have volunteer or Medicaid transportation services, but these services do not meet the need and are difficult to obtain. Many older people hesitate to ask for help with transportation because they fear being a burden. Public transportation is not always available and may be difficult for frail or ill patients to access. Some patients travel over a hundred miles to see a provider. Other major barriers experienced by older patients include lack of knowledge (e.g., about treatment options, and that many cancers can be treated) and cost (e.g., inability to pay for drugs, even with insurance; slow reimbursements; lack of Medicare coverage for home health care and basic assistance services).

## **Recommendations**

- Insurance companies should be offered incentives to waive copayments for cancer screening to encourage utilization. Clinicians must be educated on the importance of providing or referring patients for screening, including Pap smears for women over age 45.
- Public education still is needed on the importance of cancer prevention, risk reduction, and early detection. Primary caregivers of terminally ill family members should receive assistance such as respite care, tax relief, and other services.
- Federal funding is needed for screening programs for the uninsured; this should include screening for colorectal and other cancers. Funding for diagnostics and treatment is as important as screening monies. Communities and providers cannot continue to absorb these costs.
- Greater national attention and incentives are needed to encourage volunteerism, particularly in the areas of cancer treatment and care.
- Access to health care must be improved, especially in poor rural counties. Innovative solutions are needed to enable individuals to pay their own way but not face financial hardship to access care. All individuals should have the same access to cancer care.

## **DR. CARLOS SANDOVAL-CROS**

### **Key Points**

- The field of psycho-oncology is only about 10 years old. It addresses not only the psychological impact of cancer on patients with the disease, but also the attitudes, beliefs, barriers, and lifestyle issues that may influence cancer risk.
- Hispanics are a heterogeneous population living all over the world. They are neither just a racial group nor just an ethnic group; they are a little of everything. Though Spanish is their common language, significant variations exist across the vocabularies of Hispanics from different countries. These differences must be accommodated when developing cancer literature. In addition, many Hispanic immigrants are from low socioeconomic backgrounds and are functionally illiterate in Spanish, which makes them even more illiterate in English.
- Many Hispanic immigrants and migrant workers have almost no access to health care. In addition, many have “irregular” legal status that limits their access to care.

- The typical Hispanic diet is low in fruits and vegetables and high in starches and pork products. Many Hispanics from lower socioeconomic groups are unfamiliar with modern medical technology. In addition, most Hispanics do not believe that a person is supposed to actively try to maintain health and prevent disease. Instead, one is either sick or healthy, and fatalism is common. Cancer is assumed to be a death sentence, and treatment is therefore considered useless.
- Most Hispanics are extremely religious, although several religions are followed, and may believe that cancer is a punishment or God's will, or that only faith can heal them. To get some patients to accept treatment, it is necessary to persuade them that God also works through the physician.
- Dr. Sandoval-Cros recounted the case of a 75-year-old Cuban woman who had Medicare and a regular doctor and was a city dweller who was able to get around. However, she ignored a lump in her breast, believing it would go away. Even when it ulcerated, she did not seek care because she believed it was a punishment from God—her only barrier to effective care was cultural.
- Families are very involved in members' health care; whole extended families may come to doctor's appointments.
- Respect for authority figures is a cultural value for Hispanics. However, this can cause them to not question the physician or seek a second opinion. For some treated by solo practitioners or in busy HMOs, this reluctance to question their care results in late diagnosis of cancer.
- Hispanics are not impressed by a physician's credentials; they tend to value personal referrals and the personal touch of the physician.
- Hispanics need to be educated that clinical trials are quality care, not experiments being performed on them.
- Health care providers need to be aware that Hispanics may not be able to comply with suggested treatment because they cannot take time off from work or have no one to care for their children.

## **Recommendations**

- Cancer information translated into Spanish must be linguistically and culturally appropriate and must be translated by someone whose first language is Spanish. Materials also must be educationally and culturally specific.
- Provision must be made to include families in the care process.
- The role of faith and the inclusion of clergy are important to improve access in Hispanic populations. The medical community should actively seek out and train local clergy, incorporating them into the care system.
- Community groups and the media must be employed to reach Hispanic populations; for some populations (e.g., middle-class housewives in Miami), radio is a more effective communication tool than television.
- More minority health care workers must be recruited. Cross-cultural training should be provided to health care providers.

## **MS. BARBARA KUBILUS**

### **Background**

The Health and Fitness Program of the YWCA of Greater Miami has three components. The program facilitates breast and cervical cancer screening for uninsured women, including rescreening; it provides breast and cervical health education, information, and resource referral; and, most importantly, it provides

support services that include, but are not limited to, transportation and translation in both Spanish and Creole, the two main non-English languages used in the county. The program provides childcare and emotional support, and staff will accompany women to appointments and visit them at home to discuss test results.

The goal of the program is to eliminate the barriers to quality care for the medically underserved women of South Florida. More than 12,000 women have been served; 70 percent have been Hispanic, 20 percent African-American or black (e.g., from the Caribbean, including Haiti and Jamaica), and 10 percent white or other race/ethnicity.

### **Key Points**

- Lack of insurance is a principal barrier to care for program participants. Miami-Dade County has the highest rate of lack of insurance of all urban areas in Florida: 24.6 percent. Most of this uninsured population is minorities.
- Recent data indicate that only 38 percent of uninsured Hispanic women and 41 percent of uninsured black women received a mammogram in the prior 2 years, compared with 67 percent of insured Hispanic women and 66 percent of insured black women.
- Ninety-five percent of the YWCA program's clients are working, but either have no insurance available through their jobs or cannot afford premiums for employer-based insurance. In the county, 30 percent of families of four earn less than \$15,000 a year. Low-cost and affordable cancer screening and diagnostic services are extremely limited in the area. Only two facilities in the county offer treatment services to uninsured women.
- Other barriers include lack of information about community health services and resources, lack of cultural sensitivity, limited outreach to communities in need of services, lack of support services, language barriers, and lack of assistance in accessing followup care.
- To overcome some of these barriers, the program has developed partnerships with community-based health centers that serve the target community and with hospitals that offer reduced rates for screening, diagnostics, and biopsies. In addition, the program advocates for the populations and pushes for legislation. Education is provided in the places where the target population is found: health fairs, churches, community events, factories, *bodegas*, cafeterias, and adult night schools. Women are assisted to understand test results and helped throughout the care process.

### **MS. MARIE-JOSE LEDAN**

#### **Key Points**

- Many Haitian immigrants in South Florida have no legal status and are afraid to seek medical care because they believe they will be turned in to the Immigration and Naturalization Service (INS) and deported. Language and financial barriers also hinder access. People making minimum wage cannot afford insurance, and without legal status, they have no access to Medicaid or Medicare. Even with a sliding fee scale, most of this uninsured population cannot afford the sums demanded by hospitals prior to admission—unless the patient is in the emergency room.
- Uninsured Haitian men and women from higher socioeconomic backgrounds still cannot afford to receive cancer care in the United States; most now go to the Dominican Republic or to Cuba, where care is more affordable.
- Haitian women are the backbone of the family. They often ignore their own health needs in order to take care of their families. Many also work two and three jobs and send money home to relatives. They prefer not to know if they have a problem. Haitian men have high prostate cancer rates but

avoid care because they resent the rectal screening examination and because they believe they are too *macho* to need care. Because of these factors, both men and women usually present at the emergency room with advanced disease.

- As with other populations in the area, transportation and childcare problems pose barriers to care.
- Many do not want to know if they have a health problem. In addition, Haitians are very religious and believe sickness is a punishment from God for wrongdoing. For this reason, people may hide an illness from their neighbors to avoid being judged. They rely on the prayers of family, friends, and clergy, hoping for a miracle.
- Haitians also believe in the supernatural and in curses. They believe the doctor is unable to see the real problem and disbelieve test results or medical recommendations. Traditional healing, dispensed by voodoo doctors, is often sought. Home cures (e.g., rubbing hot castor oil on a palpable breast lump) are commonly used.
- Haitian Women of Miami has been successful in educating women about breast cancer and bringing them in for screening. It also has been possible to hire a part-time staff person who speaks Creole and to secure low-cost and no-cost mammograms for women. However, more education and more materials in Creole are needed.

### **Recommendation**

- Guidelines should be changed so that mammography is routinely available to women aged 40 to 49.

## **MS. SHERRY DAVIS**

### **Background**

Following a diagnosis of breast cancer in June 2000, Ms. Davis had surgery and was referred for chemotherapy and radiation. However, neither she nor a nurse from a rural health service could find a physician willing to accept Medicaid. Ms. Davis searched three counties before finally locating a doctor who would treat her. The doctor told her that most physicians refuse to accept Medicaid because it takes so long to pay—or never pays at all. She is concerned that she will have similar problems finding a provider for her radiation treatments.

Because Ms. Davis also takes an expensive medication for a heart problem, Medicaid denied her medication to control chemotherapy-related nausea, saying that it was too expensive. She has had to rely on samples of the medication she has gleaned from various sources.

### **Key Points**

- Young black women are not being educated as to the care they should receive. People with government insurance or low incomes are not treated with respect.
- Ms. Davis emphasized the importance of going to the doctor; she would not have had her cancer diagnosed if she had simply listened to the advice of friends and family concerning the breast lump she detected.

## DISCUSSION—STATE OF FLORIDA

### Key Points

- Experience has shown that the medical community and clergy can be effective partners in cancer education and cancer care. However, it is up to the medical community and the government community to reach out to clergy, not the reverse. Dr. Hiatt indicated that the NIH would likely entertain proposals for demonstration projects focusing on the church as a center of social cohesion to encourage change and health-promoting behavior in Hispanic populations. Such research has been conducted in African-American communities.
- Studies have shown that the use of alternative medicine is widespread among Americans. Hispanics and other minorities in the Miami area use a wide variety of herbal remedies. Spirituality, to some extent, can be considered an alternative therapy. In Miami, some Cubans and Haitians practice *Santería*, which involves psychospiritual and herbal practices. Most patients do not tell their doctors about alternative therapies, principally because the physician does not ask. Some alternative therapies are available in health food stores and can be dangerous to the health of individuals with certain medical conditions. These therapies also can negate or weaken the effects of chemotherapy.
- Materials developed for one Hispanic population can be used with people from a different country with little difficulty as long as the translation from English to Spanish is accurate. Dr. Sandoval-Cros reiterated the importance of having translators whose first language is Spanish.
- In Florida, Tobacco Settlement funds have been designated for a campaign to stop youth smoking, but no funding has been allocated for cancer care programs. Tobacco use among Hispanics in Florida is high. Along with poor diet and alcohol use, tobacco is a major cancer-promoting lifestyle factor.
- In Florida, the positive or negative effect of managed care depends on the particular plan and a person's location in the State. Those in more urban areas and/or with private (versus government-sponsored) plans are likely to have better access to cancer care.
- Providers need regular cross-cultural training so that they understand Hispanic culture, religious practices and roles in the community, and customs that may impact health.
- To better understand the effects of culture on cancer, researchers from disciplines such as cultural anthropology should be involved. Several such studies have been conducted in Miami.
- Ms. Blake cited a small, unpublished study of uninsured women in the State Breast and Cervical Cancer Screening Program showing that compared with diagnoses recorded in the Florida Cancer Data system, uninsured women were 75 percent more likely than those with insurance to have late-stage diagnosis.
- NCI has funded studies in specific geographic areas comparing cancer outcomes among people with different types of insurance. Some studies have shown that people in some HMOs receive screening and preventive services at rates equal to or exceeding those in FFS plans. More importantly, studies have shown that the poorest of the poor who qualify for Medicaid actually fare better in terms of outcome than the working poor who have too much income for Medicaid but cannot afford insurance.
- Many politicians believe that everyone has access to cancer care because we have emergency rooms; thus, all cancer patients are eventually treated. However, those whose only treatment is in the emergency room are unlikely to have good survival prospects. Even in some segments of the scientific community, the importance of having insurance has been minimized. More study on the impact of lack of insurance on cancer outcomes is needed.
- Florida has four cancer centers, located in Miami, Tampa, Orlando, and Gainesville.

## **ALABAMA**

### **Presenters**

**Ms. Viki Brant**  
**Dr. Shelby Sanford**  
**Dr. Mona Fouad**  
**Ms. Rosa Hill**  
**Ms. Joette Whitlow**

### **MS. VIKI BRANT**

#### **Background**

In 1990, Alabama was ranked 45<sup>th</sup> in the Nation for median household income; this ranking had improved to 33<sup>rd</sup> by 1998. Alabama tends to place at or near the bottom of State rankings on a variety of indicators of health and living conditions. The compounding nature of the conditions assessed by these indicators creates the broad-based underserved population of the State. This is most severe in the central part of the State, which also is where the majority of the African-American population resides.

Alabama also has a large population living in extreme poverty; this population comprises 20 to 25 percent of the residents of some counties. Avoiding poverty is highly correlated with being able to work and having access to work that provides a living wage. In this regard, employment continues to be a problem for the poor and working poor in Alabama.

Educational attainment is low in many parts of the population. In some counties in the central portion of the State, 30 percent or more of the adult population is functionally illiterate. This creates a major barrier to cancer education and to communicating health messages of any kind.

Alabama has a large rural population that has limited access to care. Though the State average is one physician per 2,000 residents, this ratio ranges from 1:257 to 1:11,000.

Twenty-six percent of Alabama's population of 4.4 million is African-American; this population is three times more likely than whites to be poor. Other minorities make up only 2 percent of the population; however, Alabama is experiencing the third fastest-growing Hispanic population in the country.

#### **Key Points**

- Of the women served by the State Breast and Cervical Cancer Screening Program, 54 percent reported gross annual incomes of less than \$10,000. Though the Program has provided services for some women who otherwise would not be able to access them, it is reaching only about 15 percent of those in need. One screening program in the State has successfully linked with the Welfare-to-Work Program for outreach activities to improve both employment opportunities and cancer care.
- With limited resources and multiple barriers, cancer control is a challenge in Alabama. Transferring knowledge from research and teaching facilities to the medical providers caring for underserved populations is slow at best and nonexistent in some areas. In many cases, there is no incentive to do so.
- It is quite difficult and costly to get state-of-the-art care to rural poor communities with physician ratios of 1:11,000. Transportation is a major issue, as is time off from work—even if one has a job or insurance to pay for services. Incentives are needed to encourage researchers to apply their findings to the real world in real communities such as these. The NCI Special Population Networks (SPNs) are a step in that direction. In Alabama and Mississippi, the SPN is being used to link communities with



services and clinical trial opportunities, applying the Community Health Advisor model. Through the SPNs, minorities are being recruited to become research partners.

- People with treatable cancers are not receiving the most appropriate care due to cultural beliefs, fatalism, and the costly and complicated health care system. To help overcome some of these barriers, Breast and Cervical Cancer Program staff provide clients with stamped envelopes in which to send bills received from providers so that they can receive help in understanding them and in navigating the health care system. In addition, more than 200 African-American women have been trained as Community Health Advisors to raise awareness and recruit women to screening and help them navigate the system. Using this model, one county has served 32 percent of its in-need population. However, such programs are both time-intensive and costly, which has prohibited statewide implementation. It also is true that even if the program was implemented statewide, funding and provider capacity would be insufficient to provide early detection to all women in need.
- The recently passed Federal law to provide treatment for women whose breast or cervical cancer is detected through Federal screening programs has been an important step forward. The next challenge is to get State Medicaid agencies to agree to provide this coverage.

## **Recommendations**

- Patient Navigators are needed to assist poor patients in accessing cancer care.
- Any new federally funded screening programs should at their outset provide for treatment of detected abnormalities.
- States administering screening programs need to be allowed enough flexibility to coordinate the ancillary support services that must be in place for quality services and followup care to be provided in a timely and appropriate manner.

## **DR. SHELBY SANFORD**

### **Background**

Believing that oncology care could be delivered to the rural sector by interconnecting urban and rural practices, Dr. Sanford gathered a group of medical and radiation oncologists and formed a multispecialty oncology professional corporation known as the Southeast Cancer Network. This network sees about 20 percent of all cancer patients in Alabama. Sixty to seventy percent of the practice is rural oncology. Dr. Sanford works in two clinics, seeing 40 to 50 patients a day between the 2 facilities. In addition, 20 to 30 radiation therapy patients are seen daily in these facilities. The Network has built 5 new 7,000- to 10,000-square-foot facilities in towns as small as 3,500 people. These facilities have new, state-of-the-art equipment, including three-dimensional conformal radiation equipment.

The Network includes two urban practices. The rural and urban facilities are connected by T1 telecommunications lines. Since the Network was formed, no cancer patient in Alabama is over 60 miles from a cancer treatment facility. The Network has been financed (\$20 million) entirely with funds provided by the partners; no venture capital was sought.

### **Key Points**

- The partners in the Southeast Cancer Network believe the way to breach the barriers to access is to do something rather than just talk about it.
- The Network also has a contractual research relationship with the University of Alabama at Birmingham (UAB) to enable rural patients to access clinical trials. Patients can be registered in the database with information sufficient to tell the patient at the initial consultation whether he or she

might qualify for a clinical trial at UAB and to provide contact information. Many patients need reassurance about trials, and the physicians at the Network help patients feel empowered to make informed decisions about their treatment for themselves. For those who choose to participate in a trial, treatment can be provided at the rural site, under the direction of UAB, in up to 80 percent of cases.

- A keystone of the Network is trust and honest communication with patients about the benefits and limitations of various treatment options.
- Patients from small rural towns often distrust what the doctors say, the promised outcome, and the promised lack of side effects. Survival statistics comparing treatment options are not of value; these patients want to know if they are going to be cured or not.
- Dr. Sanford cited a statement by former NCI director Vincent DeVita that to double breast cancer survival, it was necessary for every woman to receive recently developed chemotherapy, because tests did not yet exist to enable physicians to know with certainty who needed the treatment and who did not. Such tests for breast and other cancers still do not exist, so access is the key to reducing cancer mortality regardless of ability to pay, educational status, race, sex, or creed.
- As a private company, the Network receives no government assistance. Every patient is treated, regardless of ability to pay. If patients are sent to UAB for a trial and do not qualify, but they return to the Network for care, they are still treated—even if they cannot pay.
- Patients with Medicaid have trouble finding physicians to treat them, in part, because Medicaid does not pay physicians enough to cover the cost of providing care. In addition, it costs money to file the claim; Dr. Sanford suggested that it is almost better to just take care of the patient and not file the claim.

## **Recommendation**

- Making a difference in cancer care will require all of us, including physicians, to become involved as patient advocates. Policy and reimbursement changes are needed to help empower physicians to take care of all patients, but commitment to better care for all patients is the essential underpinning of change.

## **DR. MONA FOUAD**

### **Background**

Reach 2010, a project funded by CDC and other agencies, is designed to eliminate disparities between minorities and whites in six priority areas, with a focus on breast and cervical cancer. A community action plan to bring academic, State, and private sector agencies together will be developed to address community needs. Six rural and three urban Alabama counties that have large African-American populations and high breast and cervical cancer mortality rates have been selected as target areas for the program. Focus groups and surveys have been used to help identify local needs. The program has recruited 84 Community Health Advisors to help women access screening, treatment, and followup services.

Alabama Cancer Registry data for 1996-1997 show that there still is a disparity in breast cancer incidence in younger African-American women compared to younger white women. About 45 percent of cases in African-American women occurred in those under age 55, as compared with 32 percent in white women. In addition, all ages of African-American women with breast cancer in Alabama present at later stages of disease.

## **Key Points**

- Barriers identified through focus groups include: fear of cancer, fatalism, perceived lack of support from community systems, lack of understanding by or respect from providers, and lack of access.
- The Community Health Advisor model can reach target women effectively and help them get needed services, but the support of health care providers and churches is essential to success.

## **MS. ROSA HILL**

### **Background**

Ms. Hill is a 7-year survivor of breast cancer. She had no problems in accessing treatment, but her limited insurance left her with a high balance to pay. She was able to get assistance from a social worker, who helped her find financial resources to cover her hospital bill. When she developed lymphedema following her treatment, she found great help in talking with another survivor with the same condition.

### **Key Points**

- Resources may exist to help patients cope with medical bills, but the system makes them difficult to discover and discourages participation by requiring excessive paperwork.
- A significant number of older women are caring for grandchildren. These women worry about living long enough to see the children into adulthood. Because of this responsibility, these women may ignore their own health needs.

### **Recommendations**

- Information about cancer should focus on survival rather than mortality; people will be more willing to seek treatment and listen to difficult issues if they believe there is hope.
- Education about breast cancer needs to begin earlier in life, since women can develop the disease as early as their twenties.

## **MS. JOETTE WHITLOW**

### **Key Points**

- Physicians need to take patients more seriously when they report symptoms, even if there is no family history of the particular disease that may be indicated by those symptoms.
- Patients sometimes have to try several similar prescription medications before they find the one that is effective for them; these prescriptions are expensive. A no-cost trial period should be possible to help relieve patients of the burden of paying for drugs they cannot use.
- Patients, particularly those with rare diseases, need help finding information and clinical trials, as well as guidance from the medical establishment to help them select the best possible care.

## **DISCUSSION—STATE OF ALABAMA**

### **Key Points**

- Rural cancer patients need access to the best equipment, computers, and doctors, but such care also requires the best reimbursement. However, economies of scale often cannot be applied in the rural

setting since, for example, there are fewer patients per nurse, per vial of Taxol, or per square foot of building to dilute fixed costs.

- Dr. Sanford noted that due to changes in reimbursements for medical oncology drugs (including supportive drugs such as Heparin and Neupogen), one of the Network's clinics has gone in 1 year from having a profit of \$500,000 to losing money. The Network's sites are legally classified as office practices. Unlike in the hospital setting, chemotherapy administration costs (e.g., supplies) are not reimbursed by Medicare or private insurance, even though the same supplies are used. Even in urban settings, drug reimbursement margins are razor thin. The Network relies on its radiation oncology reimbursements to offset financial shortfalls in medical oncology reimbursements.
- Unlike other workers (football players, bus drivers, many other professions), physicians cannot organize concerning fiscal issues without breaching antitrust policies, although they can and do lobby for legislation.
- Paperwork is a continual intrusion on patient care.
- Health Professional Shortage Areas (HPSAs) specifically for rural oncology, with empowerment zones, are needed to help bring cancer resources to the rural market. HPSAs have proven useful in improving primary care capacity in underserved areas. Under HPSAs, physicians have more bargaining power, are less subject to antitrust policy, and can receive higher reimbursements.
- People in rural Alabama fail to get cancer care because they lack a reliable car or money for gasoline. To try to overcome such transportation barriers, the Network targets areas of 100,000 to 150,000 Alabamans in a circular catchment area who must travel at least an hour to the nearest cancer treatment facility and places a Network facility at the epicenter of that catchment area. Volunteer organizations are established at the center, and partnerships are established with community organizations, including the local hospital, hospice, and churches. Transportation, including vans and church volunteer services are facilitated. The Network has contributed to not-for-profit entities that provide transportation but does not offer transportation services directly. Transportation is a key barrier, particularly because patients are likely to have to visit the treatment facility or doctor 40 to 60 times in a 12-month period. Without transportation assistance, many patients are likely to refuse treatment.
- Ms. Hill indicated that she only found out that assistance with her hospital bill was possible because she overheard the conversation of another patient in a waiting room. Had she not inquired as to how this other patient, who had been placed on the indigent care list of the hospital, intended to pay her bill, she never would have known that financial assistance was available. Neither this information nor the help of a social worker were ever offered. Ms. Hill filled out the requisite paperwork and was eventually certified for indigent care. Her eligibility has to be recertified every 6 months. She emphasized that patients unable to pay could be saved a great deal of mental anguish if they were told that help was available.
- Ms. Whitlow found most of the information she needed at the local university School of Medicine, where she found someone to help her understand the medical terminology with which she was unfamiliar. She now has a medical student helping her to research information on her disease. Information in layman's terms would be extremely helpful to patients. Dr. Hiatt indicated that NCI is working to find ways to help more people access cancer information via new technologies and the Internet. It was noted that for patients without access to Internet information, other ways of disseminating information to the community, such as Community Health Advisors, are crucial.
- Poverty, education, and culture are more important than race in issues of access to cancer care in central Alabama. Greater sensitivity to these factors, as well as Patient Navigators, is essential for this population to successfully access needed services.
- *Extreme poverty* refers to those with earnings that are half of the Federal poverty rate.

- Because of a shortage of personnel and some lack of priority among UAB researchers, the effect of low literacy on late diagnosis of cancer has not been studied in Alabama. Such a study would probably be illuminating, since it is known that the forms people must complete in medical facilities are written at far too high a reading level for the functionally illiterate. The situation is compounded when the patient's first language is not English.
- The Veterans Administration (VA) health system in Alabama is exceedingly bureaucratic; patients have such long waits for appointments that they may have more advanced disease by the time they are seen, and they have no recourse but to use this arcane system. Dr. Sanford believes the private sector could be instrumental in improving care for this population. Due to the VA's provider contracting procedures, many veterans in rural Alabama can only access care at great distances from their homes.
- Because of the reimbursement reductions previously described, the future of the Southeast Cancer Network looks bleak. Since it is not possible to dramatically increase patient volume in a rural market to make up for lower reimbursements, it is estimated that the Network might not survive more than a year or two unless there is some relief in the area of reimbursements. If the Network goes out of business, rural Alabamans will be left with the previous care system, in which the closest care for many would be a 50- to 70-mile drive one-way. As before, many patients may refuse to seek care. In addition, most cancer treatment now is truly outpatient. The Network not only provides treatment but also manages treatment side effects, an unprofitable role for the rural hospital. If the hospitals avoid providing such care, it is the patients who will suffer most.

## **SOUTH CAROLINA**

### **Presenters**

**Ms. Joyce Hudson**

**Mr. Sam Frost**

**Ms. Irene Prabhu Das**

**Ms. Shauna Dominic**

**Mr. Gilbert B. Zimmerman**

**Dr. Mark O'Rourke**

### **MS. JOYCE HUDSON**

#### **Background**

While in her thirties, Ms. Hudson was diagnosed with breast cancer. Because of her fear of the disease, however, it was not until some time later that she sought care. In 1995, she underwent bilateral mastectomy. Little information about breast cancer or support services was available in her community. She sought help from friends, including one who worked at Johns Hopkins Medical Center. Following her cancer surgery, Ms. Hudson wanted to have breast reconstruction surgery, but her insurance company refused to cover the procedure. She discovered that the policy provided up to \$250,000 coverage for a mental breakdown. When she threatened the company with a claim for that condition, they relented and provided coverage for the reconstruction.

As a result of her own experience, Ms. Hudson became an outreach worker for the American Cancer Society. As part of this work, she formed a breast cancer support group for African-American women in her area that has enlisted 150 members to date. She also transports ill patients to treatment and other appointments.

## **Key Points**

- Some patients lose the will to live when they are unable to keep medical appointments because of transportation issues.

## **Recommendations**

- Support groups are needed to help women obtain information prior to treatment and to help them make treatment decisions. Support groups usually are available only for women who have already had treatment.
- Patients should receive information in writing that spells out exactly where they need to go, whom they are to see, and what will be done. Support and navigation assistance are essential to help people with cancer understand the procedures and processes of obtaining care.

## **MR. SAM FROST**

### **Background**

In 1995, Mr. Frost had a PSA level of 4.0. He was advised to be tested annually so that if the level rose, indicating possible prostate cancer, he would be able to intervene early. Because of his fear of the disease, he did not comply with this recommendation. In 1997, his PSA tested at 8.7. He underwent a biopsy and bone scan and was told to call the doctor for the results. Again, due to fear of hearing a diagnosis, he did not call, and the physician had to seek him out to inform him that he had prostate cancer.

Subsequently, Mr. Frost underwent prostate surgery. He experienced postsurgical difficulties due to scarring in the neck of the bladder. In addition, he believes he was not informed adequately about the possibility of impotence following the surgery. Beyond the information provided by his physician prior to his surgery, Mr. Frost did not become educated about prostate cancer until he became involved with the Best Chance Network following his treatment. He has since become a community cancer educator for the Network.

### **Key Points**

- Compared with other cancers, funding for prostate cancer seems inadequate.

## **MR. GILBERT B. ZIMMERMAN**

### **Background**

A few months after his 50<sup>th</sup> birthday, Mr. Zimmerman's sister, a nurse, began urging him to be screened for prostate cancer. Although his father and his father's oldest brother had had the disease, Mr. Zimmerman believed he was not vulnerable and ignored his sister's advice. Shortly thereafter, during Prostate Cancer Screening Month, Mr. Zimmerman found he could not ignore the many advertisements encouraging men to be screened. He made an appointment, was screened, and was found to have early-stage prostate cancer. He was treated successfully a few months later.

Mr. Zimmerman works with disadvantaged populations in rural South Carolina as both a human services program director and a cancer survivor, providing support, prevention, and treatment information.

## Key Points

- In Beaufort and Jasper Counties, South Carolina, morbidity and mortality from prostate cancer is particularly high among African-American men. Lack of understanding about the disease and a prevailing secrecy about it are major factors contributing to the statistics. The mostly low-income minority men in these two counties are reluctant to seek medical assistance because of mistrust and embarrassment. In many instances, this reluctance has caused needless suffering and death. In addition, many of these men live on fixed incomes or work at jobs with low pay and few benefits, if any. Most are employed in tourism-related service jobs.
- Disadvantaged populations have a particular need for support systems that will help them negotiate the health care system. These populations are likely to view a cancer diagnosis fatalistically, because they are accustomed to having very limited resources (either monetary or in terms of services) available to them.
- To be poor, minimally educated, a member of a racial minority group, living in the very rural areas along the coast of South Carolina, and trying to access quality health care is truly to come to grips with the word *disadvantaged*. These people are particularly disadvantaged because they cannot afford quality health care. Many, notably older residents, have transportation problems; no public transportation system is available on a convenient schedule. The population is highly distrustful of the health care system and the white professionals in it; the Tuskegee syphilis experiments have not been forgotten. Furthermore, some of the population are members of an African-American subculture, the Gullah. They speak a different language and tend to have little formal education. These individuals are often looked down upon by health care professionals who consider them ignorant or unintelligent.

## Recommendations

- The barriers to screening and treatment for prostate cancer among African-American men in rural South Carolina are numerous. Intensified collaborative efforts at the Federal, State, and local levels are needed to overcome health disparities experienced by this population and eliminate barriers to quality health care among the disadvantaged.

## MS. IRENE PRABHU DAS

### Key Points

- To identify barriers to screening and care for breast and cervical cancer, studies have been conducted on the approximately 45,000 women screened over the past 10 years through the State screening program, known as the Best Chance Network. Most of the women screened are older, minority, rural, uninsured, and living below the poverty line.
- The patient-physician interaction has been identified as an important barrier. This interaction is usually crisis-centered, since the population typically does not seek out wellness care, and is not conducive to recommending health-promoting behavior (e.g., screening). However, other studies have demonstrated the importance of physician recommendation in encouraging screening utilization. Interaction with the patient also is hampered by the physician's use of medical terminology rather than layman's terms. The patient's relationship with the provider is crucial to continued screening behavior, since regular screening is necessary to reduce mortality rates.
- Cognitive barriers to screening and treatment include both fatalism and a lack of reinforcement and encouragement from a woman's social support network or a person whose opinion is valued.
- Competing family priorities pose a barrier to screening; grandmothers are the primary caregivers for many families, particularly in the African-American community.

- Transportation is an issue for the rural South Carolina population; women who need to make transportation arrangements with friends or neighbors hesitate to impose upon them too many times. This barrier keeps many women from being screened regularly.
- The target population is highly mobile. The State has experimented with seizing the opportunity to do multiple screenings and cancer education when women do come in. For example, through a pilot project funded in three counties by the ACS, the Best Chance Network was able to offer colorectal screening to women who came in for breast and cervical cancer screening. A number of abnormalities were detected among those screened for colorectal cancer. Because funding also was available for followup colonoscopy, it was possible to remove precancerous polyps from two women, saving their lives.
- Other barriers to care include complex underlying issues related to empowerment of, respect for, and dignity of the patient. These considerations must be integrated into the delivery of care through provider communication by simplifying access and by addressing cost issues.
- Underserved populations already are dealing with survival issues. We must be sure that the health care system, including providers and policymakers, provides people with hope, tangible support, and solutions.

## **MS. SHAUNA DOMINIC**

### **Background**

The mission of the Office of Minority Health in the South Carolina Department of Health and Environmental Control is to ensure the development and modification of policies, programs, and services targeted toward improving the health status of the State's minority populations. The Office provides technical assistance and consultation to the Department of Health and to other agencies on minority health issues. A key strategy toward meeting the goals of the Office is the development of culturally appropriate health education prototypes.

In South Carolina, 31 percent of the population is minorities; of those, 98 percent is African-American. Little work has been done in the State to address male health issues, particularly African-American male health issues. African-American men in the State are three times as likely as their white counterparts to die from prostate cancer, the second leading cause of cancer death in this population. Only lung cancer causes more cancer deaths among these men.

### **Key Points**

- To develop a culturally appropriate health education initiative for the African-American population in South Carolina, the Office of Minority Health obtained a 1-year grant to develop a prostate cancer health communication initiative. Through a series of focus groups with both men and women of various ages, barriers were identified. These included a general lack of willingness to talk about cancer. Cancer is still equated with death, and there is considerable fear of cancer treatment and some of the invasive procedures it involves.
- Lack of education was another identified barrier. Focus group participants, both male and female, had little knowledge about the prostate, prostate health, or prostate cancer—as well as a number of other health issues. However, they were willing to learn about these matters. Participants wanted to meet in small community groups to discuss and learn about health issues that pertained to them. It is a misconception that people do not care or do not want to know.
- The strong mistrust of the health care system expressed by participants stemmed from negative experiences of the focus group participants themselves or from experiences of family members. Many



people in the rural counties stated that if you are admitted to the hospital, then you know you are going to die. This view reflects their experiences of watching grandparents die without dignity in the hospital setting.

- Though men in the focus groups expressed unwillingness to participate in preventive care because it was believed to be a sign of weakness, they nonetheless were aware that their health status was poor.
- Study participants indicated that they were treated unfairly if they were uninsured or had only Medicaid coverage; this stigma associated with being under- or uninsured was cited as a major barrier to care.
- Study participants recommended that messages about cancer be clear, uncomplicated, and consistent. Currently, messages are received from multiple sources and change frequently, causing some to reject all cancer-related communication. Participants also indicated that programs or education efforts should be community-based, not just community-placed—i.e., health education should be presented by people from the community in familiar community settings and in understandable language.
- As a result of the focus groups, the Office of Minority Health developed the Real Men Checkin' It Out Health Education Communication Initiative for African Americans. The initiative utilizes minority community-based organizations to deliver prostate cancer education in the community. Through mini-grants, the program has been implemented in nine communities and recently was adopted by a hospital-based cancer community initiative that provides education, screening, and followup through a network of volunteer providers in specific ZIP codes in four counties. The initiative uses churches as vehicles for education, and more than 600 of the 900 men screened by Palmetto Health Alliance have been screened as a result of the program.
- Education alone cannot solve the prostate cancer problem in South Carolina, but it is an important first step, particularly in the African-American community, where there is so much hesitation to discuss such issues.

## **DR. MARK O'ROURKE**

### **Background**

In 1939, South Carolina created the State Aid Cancer Program to reimburse some hospitals for the care of indigent persons with cancer. To receive aid under the program, one must have: a cancer diagnosis; referral to a hospital participating in the program; lack of coverage under Medicare, Medicaid, or private insurance; and income less than 250 percent of the poverty level. State funds are used to pay for chemotherapy and radiation therapy.

### **Key Points**

- Indigent assistance programs through which pharmaceutical companies provide cancer drugs free or at reduced cost work only to a limited degree. The application processes are intimidating, complicated, and tedious, and the companies deny the applications for a variety of reasons. Applications often are returned for more information. Many times, the company insists that the patient fill out the application without assistance, and many patients lack the ability to understand and complete the form.
- An advisory committee to the Department of Health has recommended expanding Medicaid coverage to those with incomes less than 250 percent of poverty. This change would enable participating hospitals to continue treating indigent cancer patients. In addition, South Carolina hospitals and facilities not currently under contract to the State Aid Cancer Program could receive reimbursement for the care they provide these patients. The infrastructure of the State Aid Cancer Program is in place to identify cancer patients in need of Medicaid benefits and facilitate their applications. The proposed

plan, which has broad support among the provider, volunteer, and legislative communities in the State, also would enable patients to receive extended courses of treatment as necessary. Eligibility for the program would be reviewed every 5 years.

- Most cancer care is now delivered in outpatient settings. The Medicaid cancer treatment benefit would allow these patients to be seen and treated in physician offices, as are other cancer patients. The program also would include a prescription benefit, and would allow increased access to NCI clinical trials.
- Because the Breast and Cervical Cancer Treatment Act does not provide for treatment of women whose cancers were detected through programs other than the CDC screening program or cover other types of cancer, South Carolina is in the process of applying for a waiver to enable the State to pilot a Medicaid benefit for indigent persons with cancer. Initially, the benefit will be extended to people with breast or cervical cancer, but the hope is to quickly expand the benefit to include people with all types of cancer. Federal legislation to enable these actions could make the process much easier. The State Aid Cancer Program has worked for 60 years but is no longer adequate to address the problem of providing cancer care for the indigent.
- Medicare Part B coverage is not uniform across the United States. In each State, HCFA contracts with a carrier to administer Part B for that State and gives the carrier discretion to determine which services and drugs will be covered. In South Carolina, the Medicare Part B carrier is Palmetto GBA, a wholly owned subsidiary of Blue Cross and Blue Shield of South Carolina. Unfortunately for State residents, Palmetto GBA has used its discretion to deny coverage in South Carolina for important drugs that are covered in nearly all of the other 49 States. Among these are four injected drugs used in physician offices: epoetin alfa (preoperative use), interferon, enoxaparin, and dalteparin. Medicare supplemental insurance policies are of no help since they only cover what Medicare covers. Despite a 1999 Federal legislative action to prohibit HCFA and its carriers from restricting coverage for these drugs beyond restrictions in place in August 1997, Palmetto GBA continues to restrict coverage for interferon, enoxaparin, and dalteparin.

## **DISCUSSION—STATE OF SOUTH CAROLINA**

### **Key Points**

- South Carolina received additional CDC funding to add case management services to its Breast and Cervical Cancer Screening Program; a pilot test will soon begin. No case management or navigator program has been included in the prostate cancer initiative because of limited funding and its educational emphasis.
- Explanations of all of the possible courses of treatment and options at each step of the process can be overwhelming to newly diagnosed patients. Physicians must make an effort to help patients understand what they might go through and to minimize the distrust many people in minority communities harbor concerning traditional health care professionals. This distrust causes many patients to reject the information given. Trust may be established more easily if the provider is from the same cultural group as the patient, though this is not always possible. Outreach workers, particularly in the rural and African-American communities, can be effective in educating people about the services and resources that are available and how to access them, and in conveying basic information about cancer. The program with which Mr. Zimmerman works uses African Americans with cancer as role models to show that the health care system can work effectively and can be trusted. In addition, African-American physicians are interviewed on various health topics in popular publications such as *Ebony* and *Jet*, and this material has proven useful in helping to dispel mistrust. Involving the faith community also is crucial.

- In 1997, the South Carolina Department of Health and Environmental Control implemented a Cultural Competence Action Plan to provide cultural competency training to its 7,000 employees. While it may not be possible to change the attitudes of some health care professionals who work for the State, all Health Department employees are now accountable for their behavior and interactions with minority patients. The training now is being provided in other settings, including physician's offices and teaching hospitals. The State also is conducting a grant involving students as young as middle-school age to determine how best to attract minorities to and retain them in health care professions.
- There appears to be more public focus on cancers affecting women than on those affecting men, yet men die from cancer at a higher rate than women. One factor in this disparity may be men's reluctance to seek care or cancer information.

### **CLOSING REMARKS, DAY 1—DR. HAROLD FREEMAN**

Dr. Freeman highlighted the day's testimony and thanked all of the speakers for their contributions to the Panel's understanding of cancer information and treatment issues in the region.

## **TOWN MEETING NOVEMBER 16, 2000**

In addition to the scheduled testimony held on November 16 and 17, 2000, the President's Cancer Panel held a Town Meeting to solicit input from the public on issues and problems in obtaining cancer information and cancer care. The public was invited to attend the Town Meeting to raise questions and share personal experiences. The Panel was represented by Dr. Harold Freeman, Chair, and past member Dr. Paul Calabresi. Dr. Robert Hiatt represented the National Cancer Institute on behalf of Dr. Richard Klausner, Director. Participating from the Vanderbilt-Ingram Cancer Center were Dr. Harold Moses, Director, and Dr. David Johnson, Deputy Director and Director, Division of Medical Hematology/Oncology. Dr. Reuben Thomas participated on behalf of the Meharry Medical College. The meeting was moderated by Nashville-area broadcaster Karlen Evins.

### **OPENING REMARKS**

Dr. Freeman welcomed all of the participants, outlined the basis for the Panel's series of regional meetings, and described the purpose of the Town Meeting: to hear directly from people in the region about problems they experience in accessing cancer information and care.

### **Key Points**

#### **KEN GIDDES, ATLANTA, GEORGIA**

- Mr. Giddes is a 7-year survivor of stage 4 bronchoalveolar lung cancer. To date, he has had 21 courses of chemotherapy. Except for the days on which he receives chemotherapy injections, he has not missed a day of work since his diagnosis. He has been determined to follow his doctors' instructions and also has participated in a variety of complementary and spiritual activities. Mr. Giddes' employer, a financial services company, pays his salary and medical benefits to enable him to pursue cancer support and advocacy activities. One such activity is the Caring Ambassadors Program, which encourages lung cancer survivors and their families to become educated about their disease and its treatment and promotes a positive mental attitude among survivors. The program has a database of approximately 900 people. He noted that efforts to encourage other companies to initiate similar programs have met with resistance because of liability concerns. Mr. Giddes also is involved in the international Alliance for Lung Cancer Advocacy, Support, and Education (ALCASE), which supports a telephone buddy system with more than 14,000 participants, yet is funded only by donations. ALCASE also publishes and distributes a free lung cancer manual. Mr. Giddes believes that patients are the Chief Executive Officers of their bodies and should learn everything possible about their disease. Support groups and one-to-one contact are of enormous help to patients, and their benefit should be more widely recognized, if not supported financially. Lung cancer research is underfunded compared to other common cancers and should receive more support.

#### **DR. FREEMAN**

- In recent years, the NCI has taken the issue of quality of care very seriously and has reached out to the various communities of advocates to include them in NCI's research and planning processes. Research funding levels for specific cancers reflect in part the strength of advocacy activities that have been brought to bear on those who make funding decisions. It should be remembered, however, that breakthroughs against a given cancer may come not just from research funded by targeted monies, but from research on other cancers. Therefore, we should advocate for universal support of research on all cancers.

## **DR. MOSES**

- NCI's Progress Review Groups (PRGs), composed of scientists and physicians from around the Nation (and for the most part, outside of government), review the research that is currently supported by NCI relative to specific cancers and make recommendations for research directions and priorities. Dr. Klausner and the senior leadership of the NCI have been superb in responding to the recommendations of the PRGs. A PRG on lung cancer is planned and should result in a change in the approach to lung cancer research in the future.

## **WILL SHIPLEY, TENNESSEE**

- Mr. Shipley is a health educator and exercise specialist who also has worked in the fields of physical therapy, rehabilitation, and prevention. He helped establish one of the first tobacco education programs in Tennessee. His own family has been affected by cancer. Both of his parents and an aunt and uncle have had cancer, and he recognizes that his own risk of cancer may be higher than average. He believes public health education in schools should be enhanced. Many public school systems are reducing their physical and health education programs, and these courses also have been eliminated from many university curricula. These programs are crucial to helping youth develop healthy lifestyles that will reduce their risk of disease later in life. Male health education instructors are in particularly short supply; male role models are essential to reach young males and deal with male-specific issues (e.g., prostate and testicular cancers). Web sites should be used to help reintegrate this material into curricula at all levels and make education user-friendly. People who have had cancer have an important role in helping to educate youth about cancer prevention.

## **DR. HIATT**

- Cancer prevention education for youth is essential. Those in the research arena are very concerned about how best to prevent initiation of tobacco use and encourage youth who are smoking to quit. This is an area in which we are not doing well; youth smoking is increasing. Diet and physical activity are two other critical areas, since the habits established in youth are carried into later life. Mr. Giddes remarked on the level of funding for lung cancer research. The large amounts being spent on tobacco control and other prevention research should be included in estimations of research expenditures related to lung cancer. In addition, the work being done by Mr. Giddes' group demonstrates the value of survivorship groups, and in particular, his group provides a valuable service by helping to dispel the idea that a diagnosis of lung cancer is a death sentence.

## **DR. THOMAS**

- Education in the schools is important, but education should extend to the whole family. A lot of what children learn is what they see at home. Communities and volunteer organizations have an important role in such family education.

## **RON WRIGHT**

- For the past 3 years, Mr. Wright has been fighting an unusual form of inoperable colon cancer. His original oncologist was not encouraging about his prognosis, so Mr. Wright sought care at M.D. Anderson Cancer Center, though he was subsequently referred to a local oncologist with whom he has been working for 2 years. Mr. Wright was struck by the difference in attitude and hopefulness he found there. While at M.D. Anderson, Mr. Wright learned that research discoveries made at the Center (and elsewhere) can take 5 years to reach local doctors; this is far too long for many cancer patients. In addition, Mr. Wright believes that more research and reimbursement are needed for

alternative therapies, that steps should be taken to reduce the cost of cancer care, and that the FDA drug approval process should be streamlined.

## **DR. CALABRESI**

- More research should be conducted on alternative therapies. When these are tested in controlled clinical trials and found to be effective, they become part of conventional treatment.

## **DR. JOHNSON**

- M.D. Anderson Cancer Center and the Vanderbilt-Ingram Cancer Center are among the more than 50 NCI-funded Comprehensive Cancer Centers located throughout the United States. These Centers are funded in part to help quickly disseminate research findings to the community, and it should not take 5 years for findings to reach local practitioners. NCI helps ensure that discoveries made at any of the Centers are disseminated rapidly; however, some physicians in the community and in academic settings may fail to act on this information.

The FDA is criticized for the slow development of drugs, but the agency does not develop drugs; this is done by the pharmaceutical industry, NCI, cancer centers, and others. It is incumbent upon those developing drugs to do so correctly and carefully to ensure that trial results are valid. Many of the drugs submitted to FDA for approval do not pass careful scrutiny by the agency or its independent advisors, principally because drug studies were conducted poorly. Individuals who advocate for the benefits of certain medications or certain therapies but do not properly study and evaluate them do no one a service, least of all cancer patients. Those who conduct clinical trials should ensure that patients have every possible opportunity to participate, and patients should seek out clinical trials—both because trials provide the best medical care and to ensure that drugs are tested properly. In addition, greater participation in trials means that the drug approval process will be expedited. Currently, only about 6 percent of people with cancer participate in clinical trials.

Concerning physician attitudes, it should be remembered that, like the rest of the public, physicians have different personalities, and it is true that some can become very negative. There is no easy way to tell someone that he or she has a terminal disease, and sometimes, patient perceptions of the physician stem from the message being delivered rather than the messenger. Physicians can and should, at a minimum, provide hope to individuals to assure them that their care will be provided in as scientifically valid and humane a way as possible. Physicians also should acknowledge and utilize the power of the patient's spirit.

## **DR. HIATT**

- NCI has information resources for patients, their loved ones, and any person concerned about cancer prevention. Cancer information of all types is available through the Cancer Information Service's toll-free number (1-800-4-CANCER) and through NCI's Web site ([nci.nih.gov](http://nci.nih.gov)). The Web site enables people to access information on clinical trials, local physicians who are conducting trials, and the latest evidence on the efficacy of prevention and treatment procedures.

## **GLENDIA WATKINS**

- Ms. Watkins, a breast cancer survivor, observed that while people are required to pay their health insurance premiums on time, the insurers seem to be under no obligation to pay providers in a timely manner. She also noted that following a cancer diagnosis, it is very difficult to secure full-time employment or life insurance. Having cancer is like playing Monopoly: You always get put in jail for something for which you had no responsibility. Ms. Watkins also recommended that mammography technology be improved.

## **DR. FREEMAN**

- There have been some attempts in Congress to address the issues of employment and insurance for those with preexisting medical conditions. It is both a political issue and a fairness issue that has been only partially resolved through the Health Insurance Accountability and Portability Act. Many people still feel they are stuck in unsatisfactory jobs because they fear losing their health coverage if they change employment. Resolution of both the health insurance and life insurance issues is unlikely until the public demands that legislators change existing laws and policies. This was amply demonstrated in the 1960s, when philanthropist Mary Lasker spearheaded a movement that resulted in passage of the National Cancer Act, which has led to continual increases in the NCI budget, now at \$3.5 billion. Since many issues in America are decided based on public will, those in attendance this evening can have a role in creating change on these insurance issues.

## **DR. JOHNSON**

- Dr. Johnson indicated that cancer survivors are a minority that has not spoken with a loud enough or sufficiently unified voice on these issues, which are no longer medical but political. He noted that several years ago, he was considering a position at another of the top cancer centers in the country. Upon disclosing his own cancer history and inquiring about his insurance coverage for the preexisting condition, he was told not to worry, that the Cancer Center would provide any treatment he might need, although cancer care would not be covered under the insurance plan. However, the Center refused to put these arrangements in writing, and Dr. Johnson declined the offer. His situation demonstrates that the insurance problem is not unique to those outside the medical or academic worlds.

Making the legislative changes needed to resolve health and life insurance issues will be expensive; it means that someone will have to pay the bill. However, people who are making a contribution to society have the right to an assurance that their health and life insurance needs will be covered. Dr. Johnson also observed that if testicular exams were performed in the same manner as mammograms, there would be a new mammography machine tomorrow.

## **DR. THOMAS**

- Unfortunately, considerable prejudice and misinformation remain regarding certain medical conditions. Some people still believe it is possible to catch cancer from another person. Others react negatively to a person with cancer because talking with a survivor about the disease may cause the other person to confront his or her own mortality. Health care workers have an obligation to better educate the public about illnesses such as cancer and AIDS. Survivors likewise have a role in showing the public that it is possible to live a normal life even with these types of diseases.

## **FRANK EMERSON, TENNESSEE**

- Mr. Emerson was diagnosed with Hodgkin's disease in 1983; he has had a recurrence and complications. He has had a bone marrow transplant. Following his treatment, he became involved in advocacy for cancer survivor issues and is a frequent speaker on these issues at both the local and national levels. In addition, he has been involved with a number of major cancer centers in conducting survivor conferences and exploring the role of the individual spirit in the healing process. He subsequently received a grant that he used to explore palliative care needs.

Mr. Emerson noted the current void in care that exists between curative therapies and hospice. Notable exceptions include the M.D. Anderson Cancer Center's recently initiated Symptom Control and Pain Management program, a multidisciplinary approach to planning and managing both inpatient and outpatient palliative and end-of-life care. The Franciscan Health System in Tacoma,

Washington, has placed pre-hospice nurses in oncologists' offices to better enable physicians to transition patients to palliative and end-of-life care, which includes an extensive volunteer network. This approach also avoids the situation in which curative therapies are continued inappropriately or in which the physician distances him- or herself from the patient when curative therapy is no longer viable. Duke University, in collaboration with Dr. Meador at Vanderbilt, has started the Institute for Care at the End of Life, based jointly in the divinity and medical schools. This program is generating much interest at the national level and was featured on the recent Bill Moyers series on death in America. That series noted that 80 percent of medical care costs per person are expended in the last months of life. In addition, most people do not want to die in a hospital but end up doing so. Mr. Emerson believes that with a change in focus and leadership, it would be possible to institute a far more dignified process for patients for whom curative therapies have failed.

#### **DR. FREEMAN**

- The medical establishment historically has focused on cure and, for the most part, continues to do so. Though the pursuit of cures should not be reduced, more focus is needed on prevention and on quality of life and palliation. Dahl and Peto (1981) estimated that as many as two-thirds of cancers are preventable, with one-third of cancer deaths due to tobacco and another third attributable to diet. Though treatment has improved, 40 to 50 percent of people do not survive their cancers. Quality of life for these people is a major concern. Dr. Richard Paine, head of the Pain Service at Memorial Sloan-Kettering Cancer Center, focuses both on pain control—a major failing of the medical community—and on providing palliation to patients who are incurable but whose quality of life can be improved through active, though not curative, treatment. The Panel addressed the problems of quality of care and quality of life in its report to the President 3 years ago; the National Cancer Policy Board also published a report on quality of care in the same year. This issue is gaining more attention than in the past.

#### **DR. HIATT**

- One way to increase attention to quality-of-life concerns is to improve our ability to describe and measure quality of life. Surveillance systems need to be enhanced to measure patient-centered aspects of disease, including quality of life, financial impact, physical performance, pain, and pain management. Currently, no agreed-upon, reportable measures of such factors exist, and these are needed to provide the information that will foster attention to these issues.

#### **DR. FREEMAN**

- Measures of quality must take cultural differences into account. What may be perceived as quality care by one population may not be viewed as such by another.

#### **DANIEL HOSKINS, CHARLESTON, SOUTH CAROLINA**

- Among the minority disadvantaged, particularly the poor, it is necessary to address health care concerns in a holistic manner. Many of the chronic diseases faced by the poor, including cancer, are influenced by diet, exercise, and lack of early detection. Barriers to care related to socioeconomic status have been documented since the 1980s and confirmed by several independent researchers. Despite this knowledge and attempts to diminish identified barriers, most of the barriers that contribute to health disparities remain. NCI should fund organizations whose primary mission is to work with the poor—such as the Community Action Agency that operates at the local level in every State—to conduct research and provide cancer education and prevention services. The health care system can be as much of a barrier as poverty itself when poor patients are treated with disrespect or with poor-quality care simply because they are poor. NIH should develop a system to share



knowledge about disparities with medical professionals of all types who are contributing to those disparities. Doctors, nurses, and technicians of all types should be sensitized to these issues, both during initial training and in continuing education, and should be held accountable for both the interventions and quality of health care they provide.

## **DR. FREEMAN**

- The newly created NCI Center for Cancer Health Disparities will have a research component aimed at identifying and exploring key questions related to disparities affecting special populations. In addition, the Center will have a Health Policy Branch that will convene the best scholars and thinkers from around the Nation and the world to consider policy changes that will reduce or eliminate disparities. Such policy changes must address the issues of lack of insurance and underinsurance, communication to people of diverse cultures, and education at all levels. In America, we see each other through the lens of race and culture and make assumptions about each other that are very often false—and sometimes harmful—without intending to harm. In addition to training for medical providers, we have to reach back and provide appropriate training to children, because people are always socialized before they are educated.

## **BOB CLAXTON**

- Mr. Claxton's wife was diagnosed with esophageal cancer 2 years ago, and she was treated with surgery, radiation, and chemotherapy. When these treatments failed, Mr. Claxton and his wife went to Mexico to receive alternative therapies not available in the United States. They encountered many other Americans in Mexico for the same reason. He questions why there is little research on alternative therapies.

## **DR. CALABRESI**

- NCI has set up an Office of Alternative Medicine, and many excellent Cancer Centers are exploring alternative and complementary therapies. For example, Barrie Cassileth at Memorial Sloan-Kettering Cancer Center is devoting her entire professional attention to these therapies. Many of the remedies and treatments that become part of mainstream medicine begin as herbal or other folk remedies. One of these, Camptothecin, derived from a tree in China, recently has been shown effective against colon cancer. It is important that alternative therapies be fully tested in clinical trials to prove their efficacy, and greater patient participation in clinical trials is needed to make this possible.

## **SHEILA GARVIN BATES, TENNESSEE**

- It was upsetting to find out that \$3.5 billion was spent on the presidential campaign (with the victor still undecided). Every day, patients call the Tennessee Leukemia and Lymphoma Society to say that because of cancer-related costs, they are losing their homes and the cars they need to get to treatment. There is a huge need for help with nonmedical expenses such as childcare, housing, and utilities, as well as with purchasing medications. The President needs to be made aware of the needs of the people. If these needs are made a priority, ways will be found to meet them.

## **BONNIE CLISELLI, ALABAMA**

- Speaking for survivors and family members with whom she works at the Southeast Cancer Network in Alabama, Ms. Cliselli indicated that key needs in the State are for cancer screening; education about cancer risk; early detection programs for low-income residents provided through local programs and local leadership; appropriate treatment and followup care, including grief education; culturally appropriate cancer information and programs for Native Americans; insurance coverage for

preexisting conditions and second opinions; information about alternative medicine; and improved pain management, particularly at the end of life.

## **HEATHER TAYLOR**

- Ms. Taylor is a two-time cancer survivor whose doctors did not expect her to survive 2 years ago. Although it meant losing her insurance, she recently left a highly stressful job and is now seeking other employment. She has been advised not to tell prospective employers that she is a cancer survivor, but she is concerned about preexisting condition clauses in the insurance coverage available through any new employer. She noted that it is neither her own nor anyone else's fault that she has cancer and that she should be able to be confident that she can be insured. Ms. Taylor also noted the extraordinary amounts charged by the hospital for medication (\$30 per Darvocet pill versus the cost of filling a prescription at the local pharmacy at \$7 to \$8 for 30 pills) or to change bedsheets (\$70 each time). Ms. Taylor questioned where this money goes.

## **DR. JOHNSON**

- Health care is undeniably expensive; expenses for some items seem outrageous. Most of the dollars go to pay for professional care, such as physicians and nurses, but they also cover often-unseen personnel such as those who run laboratory tests and conduct patient monitoring tasks. Nursing care includes chemotherapy administration, assistance to physicians in patient evaluation and care, and other duties. A large part of health care expenses has been borne by third parties, making it easy for those receiving payment to increase their fees and for those receiving care to ignore the costs. Patients need to be more involved in scrutinizing what they are getting and what they are paying for. Just because the insurance company writes the check does not mean it is not the patient's money. People who are insured seldom ask what a given regimen of care or a test will cost.

## **DR. MOSES**

- Charges to insurance companies often are higher than they should be because of the need to offset the cost of uncompensated care of other patients.

**NOVEMBER 17, 2000**

**REMARKS—DR. CLIFTON MEADOR, EXECUTIVE DIRECTOR, MEHARRY-VANDERBILT ALLIANCE**

**Key Points**

- The Meharry-Vanderbilt Alliance was formed in January 1999. Its steering committee, with representatives from both institutions, is alternately chaired by Dr. John Maupin, President of Meharry Medical College, and Dr. Harry Jacobson, Vice Chancellor of Health Affairs at Vanderbilt.
- The Alliance has five broad initiatives. Two of these are: to share and develop the clinical sciences and residency programs of the two institutions; and to open the electives of both undergraduate medical schools to each other, sharing curricula and opening library resources to both campuses. These two initiatives have been fully established. The third initiative is to share joint biomedical research and training programs, and it has been the most extensive effort to date. The remaining two initiatives are efforts that reach into the community of Nashville, Metro Davidson, and Middle Tennessee. One is the Meharry-Vanderbilt Institute for Community Health; the other is the Nashville Consortium of Safety Net Providers. The formation of these collaborative efforts has been a wonderful story of building trust, respect, and collaboration across a diversity of people and institutions.
- It was clear from the outset that both Meharry and Vanderbilt treat a disproportionate share of the uninsured, underinsured, and underserved populations in their regions. Combined, both academic centers provide subsidized care to this population or lose in excess of \$30 million per year.
- The Nashville Consortium of Safety Net Providers, now an arm of the Metropolitan Health Department, combined all the clinics in Nashville that treat the underserved. Each clinic has a representative on the board of the Consortium. In addition, all but two of the emergency rooms are Consortium members. A 30-member communitywide advisory board represents all of the local agencies and other community efforts directed toward health. The Chamber of Commerce, the Mayor's office, and others also participate. The Consortium's initial focus is to create a registry of the uninsured population of Metro Davidson County and then work to bring these patients out of the emergency rooms and into designated primary care clinics, thereby providing continuity of care and promoting earlier intervention for health problems. Ultimately, the Consortium seeks to build a system to bring the best practices in medical management, access, and care to this underserved population.
- The Meharry-Vanderbilt Alliance is establishing a virtual Institute for Community Health, bringing together scientists, epidemiologists, and clinicians who can link the outcomes of research and findings in the existing literature to the care of the underserved population. In this way, the Institute will provide scientific and clinical expertise for the consortium of stationary providers.
- The Meharry-Vanderbilt Alliance has reached out to the larger community to form a partnership designed to correct the health disparities that now exist among the minority populations of the county. The Consortium's main challenge is to build a solid collaboration with limited competitive grant funds. The hope is that when universal health coverage is finally enacted, the Nashville area will be prepared with a coordinated system of care. At a minimum, the Alliance expects to show that coordinated and systematic care yields better outcomes at lower cost than the existing fragmented system.

## **GEORGIA**

### **Presenters**

**Ms. Carol Steiner**  
**Ms. Carolyn Williams**  
**Ms. Yung Krall**  
**Ms. Venus Ginés**  
**Ms. Angela Johnson**

### **MS. CAROL STEINER**

#### **Background**

Georgia's largest minority population is African-American. Cancer accounts for 27 percent of deaths among African Americans in the State, with lung, prostate, colorectal, and pancreatic cancers most prevalent among men, and breast, cervical, colorectal, and pancreatic cancers most common among women. Prostate cancer among men and cervical cancer among women in the African-American population are twice as high as in the Caucasian population. African-American women aged 65 and older are less likely to have had Pap smears, mammograms, and clinical breast exams than older white women in the State. The Breast and Cervical Cancer Screening Program reaches only about 15 percent of eligible uninsured women.

Georgia's Cancer State Aid treatment program has been in operation since 1937. It is a public-private partnership, but it meets only about a third of the population's need.

Georgia's Governor will be announcing a new cancer initiative in the coming week, reflecting an unprecedented awareness of and interest in cancer and cancer control at the highest levels in the State.

#### **Key Points**

- Uninsured patients at Georgia's rural and other public health clinics face barriers to care that include inability to pay out of pocket (causing them to defer needed cancer treatment until their disease is far advanced) and transportation issues that keep people from accessing needed services. In one case, a patient walked 5 miles to get to a rural clinic for a pelvic exam, Pap smear, and clinical breast exam but was too embarrassed to admit she could not get to the next town, 25 miles away, to have her mammogram. Those who are seen through the Breast and Cervical Cancer Screening Program often have cancers that are detected earlier, and these women can be referred to Cancer State Aid for treatment. One such patient described the anxiety, fear, stress, and frustration of her diagnosis, which was exacerbated by her lack of insurance; she was grateful that Cancer State Aid had been available.
- Transportation in the rural areas of Georgia is a barrier to screening, and quality cancer treatment facilities are limited in these areas.
- Economics is a major burden to cancer care. Almost 38 percent of Georgians are poor or near poor; 47 percent of this population is uninsured. In addition, the State appropriates only \$2 million to treat indigent cancer patients. People who do not qualify for this program must seek cancer treatment at reduced cost from one of six county urban hospitals or medical schools in the State.
- One in four Georgians cannot read. Only limited culturally sensitive care and educational materials are available for use with rapidly growing Hispanic and Asian immigrant populations. The Health Department has partnered with the National Asian Women's Health Organization (NAWHO) to

conduct two training sessions for health professionals to teach them how to provide culturally sensitive care to this population.

- The screening program has been successful and is available in every county of the State. Any woman who wants a Pap smear and pelvic examination can receive these services, and diagnostic facilities are available statewide through local health departments and public-private partnerships. The State has gone from having the highest cervical cancer mortality rate in the Nation to a rate just above the national average.
- Similarly, any woman can receive a mammogram within 25 miles of her home. Eight privately owned mobile mammography units are in operation as a result of a public-private partnership.
- However, there remains a great fear of cancer, and some people refuse care. The State Health Department is trying to determine what interventions would be more effective in inducing women with abnormalities detected through the Breast and Cervical Cancer Screening Program to accept needed care.
- Georgia also has no NCI-designated Comprehensive Cancer Center, and opportunities for participation in clinical trials are limited.
- Important needs in Georgia include public awareness campaigns to let people know that they can influence their cancer risk through lifestyle choices and that cancer is survivable. In addition, Breast and Cervical Cancer Screening Programs need to be expanded and colorectal cancer screening initiated. Health care coverage for all residents is needed, and quality cancer treatment is needed in rural areas. The public infrastructure must be enhanced to support comprehensive cancer control, surveillance, evaluation, and health services research.

## **MS. CAROLYN WILLIAMS**

### **Key Points**

- In 28 years as a social worker at University Hospital in Augusta, Georgia, Ms. Williams has seen both great advances in cancer treatment and the deterioration of the health care system. Many physicians who care deeply about their patients have become discouraged because they cannot meet patient needs under the current system.
- Fear of cancer is a major barrier to care. It includes fear of death, disfigurement, and hair loss; fear of losing one's job and insurance; fear of separation from family; fear of being alone; and fear of side effects of treatment. Counseling can help patients with these fears, but there are few sources of counseling for the uninsured. Insurance policies often have poor mental health benefits. The trend in hospitals is to decrease social work staff, who in the past provided counseling for uninsured patients. University Hospital, for example, has reduced its social work staff from 15 people to 2, thus decreasing services.
- University Hospital recently opened a Breast Cancer Center with the goal of providing all needed services in a single location. A hotline is available to women who detect a breast lump. Upon calling, a woman can come in immediately to see a nurse practitioner. If a lump is felt, and the patient has a physician, that physician is contacted. If the patient has no physician, she is matched with one and seen that day. A mammogram will also be performed that day if needed. Biopsy, if needed, is performed within 48 hours, and every effort is made to reduce the time a person must worry about the outcome. The Breast Center also offers Reach to Recovery programs and has a salon and a boutique that offers wigs, prostheses, bathing suits, and scarves.
- Cost is another major barrier to care. Insurance companies often do not approve expensive treatments, and physicians have difficulty getting new treatments precertified. After a treatment has been

approved, the insurance company may refuse to reimburse the physician. Some physicians report losing up to \$50,000 per patient due to this situation. As a result, many physicians are reluctant to use new treatments. Since the Diagnosis-Related Group (DRG) system was implemented under Medicare, physicians have been encouraged to use the cheapest drugs available. Report cards comparing physicians' costs are routine, but there are no report cards comparing outcomes.

- Cost issues for patients when cancer is diagnosed include loss of employment and health insurance. Many cannot afford to pay COBRA premiums to continue their insurance and become uninsured. They may have difficulty obtaining any type of treatment. Uninsured residents of neighboring States who seek care in Georgia have difficulty getting into any health care system. Many cancer patients have to apply for Disability. It is routine for applications to be denied at least twice, and it may take a year or two to receive any type of funding. Some become homeless. Many feel they are a burden and discontinue treatment if they have been receiving it. Georgia's Cancer State Aid program frequently runs out of funds, and its benefits are limited to \$10,000 per patient per year. One of the biggest financial issues is the lack of coverage for drugs under Medicare. Patients frequently do not fill their prescriptions or fill them only partially.
- Transportation is a third barrier in Georgia. Medicare pays only for emergency transportation of stretcher patients; it does not pay for routine doctor visits. There is no public transportation in rural areas, and public transport is limited in Augusta. Medicaid transportation requires a 3-day notice and often is booked far in advance. Senior citizen vans also have long waiting lists. The Augusta area does not have Medicare van transportation. This lack of transportation prevents patients from following chemotherapy and radiation schedules.
- The fourth major barrier to cancer care in Georgia is the complexity of public programs. Georgia has 22 separate Medicaid programs. The public is unaware of most of these programs, and workers at the Department of Family and Children's Services are not knowledgeable about them. If a patient does not know the exact name of a program of interest, he or she will have a difficult time getting an application. Drug company assistance programs are helpful, but all have different procedures. Many have lengthy applications that have to be requested. Many physicians resist doing the paperwork involved in securing drugs for patients through these programs.
- Patients may also need home health services but can get this care only if skilled nursing service is required. Most patients need only an aide or sitter, but neither Medicaid nor Medicare will pay for unskilled care. Instead, they will send a registered nurse, whose services are more expensive. Revising the regulations of these agencies in this regard could result in significant cost savings.

## **Recommendations**

- Medicaid in Georgia should be streamlined, and the public should be made more aware of the program.
- Home health regulations should be changed to meet patients' needs in the least expensive way.
- Transportation needs to be made more available. In some areas, this could be accomplished by contracting with existing cab companies instead of inventing new agencies.
- Drug companies should be encouraged to simplify patient assistance applications.
- Counseling should be more accessible.
- The public should be educated about the restrictions insurance companies place on physicians.
- Congress should be encouraged to pass legislation to provide drug benefits for Medicare recipients.

## MS. YUNG KRALL

### Key Points

- The population of Georgia includes approximately 42,000 Vietnamese, 60,000 Koreans, 65,000 Chinese, and a host of refugees from Kosovo, Bosnia, Somalia, and Haiti. As of 1999, 103 languages were spoken in the workforce and households of Georgia. However, only English is spoken for cancer education, prevention, and treatment. Older men and women who come from war-torn countries are at risk of living with and dying from cancer before they ever get treatment.
- Liver cancer among the Vietnamese and Chinese is 14 times higher than in the white population. Vietnamese have the highest cervical cancer rate of all ethnic groups: 43 cases per 100,000 women. According to the Chinese Physicians Association, Chinese have the highest rate of throat cancer.
- Cancer in the Vietnamese population is still a stigma and a mystery. It is considered a shameful illness and a death sentence. Cancer brings a lonely death, since the disease is kept secret. Friends, coworkers, and even the children are told the person died from another cause.
- Many patients lack access to mainstream medicine and often go back to their home countries to die or seek alternative medicine. Throughout Georgia, thousands of Vietnamese send money home to Vietnam to buy medicine to treat hepatitis B.
- It is helpful for American health care providers to acknowledge old-country health care beliefs, since this creates trust and breaks down barriers between the physician, the caregiver, the patient, and the patient's family.
- Primary care physicians and referral specialists who care for Asian patients need to communicate and work together to care for the whole patient, not just the disease. Asian patients are less likely than white patients to seek second opinions.
- Partnership with the local minority Physicians Association will benefit programs that want to reach Asian, other minority, and other immigrant and underserved patients. These physicians are knowledgeable about the health status and health problems of target populations. Such partnerships also will help immigrant physicians, who are often professionally isolated in this country.

## MS. VENUS GINÉS

### Key Points

- Aside from common factors (e.g., education, finances, language) that hamper Latinos in obtaining proper screening, major gaps exist both in data collection on Latinos and in the analysis of those data. As a result, it is difficult to make assumptions about Latinos, who represent a mix of racial and ethnic lines from 22 countries of origin. These subpopulations have unique demographic characteristics and cultures in addition to differences in history and cultural background.
- Controversy exists concerning the use of the terms *Hispanic* and *Latino*. The former implies the connection to Spain and its language, while the latter represents nationality or geographic origin (i.e., Latin America). Today, *Latino* is more commonly used because it more accurately represents the new wave of immigrants and includes Brazilians.
- In the United States, Latinos continue to suffer social, political, economic, and personal oppression. There is a need to assess how systemic and cultural barriers affect Latinos' health priorities. For health care providers to understand why so many cancer prevention programs geared for Latinos are not utilized, they must understand that fear and distrust are partially due to a history of medical abuse.

For example, in 1939, the Federal Government implemented a program to reduce overpopulation in Puerto Rico by sterilizing women without their consent. By the 1970s, 37 percent of Puerto Rican women of childbearing age had been sterilized. Likewise, Mexican-American women in California were sterilized without consent, resulting in 1974 in a class action lawsuit against the Los Angeles County Medical Center. In addition, Latinos were used as guinea pigs for experiments with birth control pills and contraceptive devices. Knowledge of these events is widespread and may be a major contributor to the fear and distrust that many Latinos harbor. These fears, together with traditional attitudes and beliefs about health, are important factors in Latinos' interactions with the health care system.

- Currently available cancer education materials available to Latinos do not adequately consider literacy skills in the population. Such materials also need to be ethnic-specific (e.g., images in videos or picture books). In addition, more Latinas should be recruited to become health educators and health advocates. More bilingual and bicultural health care personnel are needed.
- Many Latinos prefer to use hospital emergency rooms, rather than community programs, when sick. Most do not have private doctors. Mexican-Americans tend to be the least insured, while two-thirds of Puerto Ricans have limited coverage through Medicaid. Some State assistance programs have stringent eligibility criteria, long waiting lines, and lengthy application forms; all of these pose barriers to participation.
- Creative ways must be found to overcome these barriers in the rapidly growing Latino population. In collaboration with the community, Ms. Ginés' program conducted a health fair for the Latino population. The Latino media have been great allies. All local clinics are invited to participate. The health fair was just conducted for the fourth time. At the first fair, 286 women registered; this year, 604 women registered. Local merchants donated food; local churches distributed literature. In addition, oral screening and immunization programs were available for children while their mothers were being screened. Entertainment was provided, and the fair itself was located across from the Metro station to help ensure accessibility. In addition, Latino major league baseball players attended, enhancing the program's appeal. The Governor's wife also attended. Other activities and donations helped make the all-volunteer fair a success. This year, the fair also included a prostate cancer education tent. The fair is now an established community event. Moreover, President Fox of Mexico has been made aware of the health fair; he is interested in working through Mexican consulate offices across the United States to implement similar health fairs for Latinos across the country.

## **MS. ANGELA JOHNSON**

### **Background**

Ms. Johnson is a 47-year-old mother of two adult children, one of whom is disabled and totally dependent. Ms. Johnson works full-time for the Macon/Bibb County Economic Council. She was diagnosed with stage III breast cancer in February 2000. She was fortunate to receive prompt diagnosis and treatment, full information, and the support and involvement of her family. Although she experienced some complications, in part due to being diabetic, she has completed her initial treatment. All but approximately \$1,700 of her \$37,000 medical bill was covered by her insurance.

In the course of her own treatment, she spoke with many women who avoid screening and treatment because they have no insurance and cannot afford care. Many also worry about childcare and loss of their jobs.

### **Recommendations**



- Medicaid should be revised or a new program initiated so that low-income people can obtain health coverage at a premium they can afford.

## **DISCUSSION—STATE OF GEORGIA**

### **Key Points**

- CDC's role in cancer screening should be expanded. Programs similar to the Breast and Cervical Cancer Screening Programs could be developed for colorectal cancer.
- To address the high liver cancer rate among Vietnamese, which is related to hepatitis B infection, Ms. Krall worked with the State public health and refugee health programs to screen all new arrivals for hepatitis B. She also approached CDC, which responded by recommending newborn vaccination and health education for adults. Ms. Krall advocated for inclusion of a hepatitis B test for Vietnamese couples applying for marriage licenses but did not get agreement on that policy. She now is trying to get CDC to help her program with hepatitis C education and vaccination. However, she noted that since she is a community volunteer rather than an organization, it has been difficult to get assistance from CDC.
- The term *Hispanic* was first used in the 1980 census. The decision to use it was made by a committee of three who decided it was most appropriate since this growing population all spoke Spanish. However, there are significant differences among the Spanish spoken by people from Mexico, Central America, Latin America, and Spain. In fact, three different terms for breast cancer are used, depending on where in Latin America the speaker comes from. In addition, Brazilians are included in the Hispanic statistical category although they speak Portuguese. Filipinos speak Spanish but are considered Asian/Pacific Islanders. People in Texas and Florida are more likely to refer to themselves as *Hispanic* because the population there has strong Spanish ancestry; those in most other States refer to themselves as *Latino*. Those who favor the term *Latino* do so because they prefer to be identified by their nationality rather than their language.
- Only 14 to 15 percent of women eligible for the Georgia Breast and Cervical Cancer Screening Program are being screened. Over the past 6 years, approximately 35,000 women have been screened, but there remains a large population that is not being reached.

## **U.S. VIRGIN ISLANDS**

### **Presenters**

**Ms. Deborah Richardson**

**Ms. Debbie Christopher**

**Dr. William Fogarty**

**Ms. Dorothy Straun**

## **MS. DEBORAH RICHARDSON**

### **Background**

The United States Virgin Islands (USVI) is an unincorporated territory of the United States comprising four islands: St. Thomas, St. Croix, St. John, and Water Island. Total population (1995 Survey of Population and Housing) is 109,661, a 7.7 percent increase from 1990. There are approximately 7,000 more females than males. The population is 77 percent African-American, 10 percent Caucasian, and 13 percent other races/ethnicities. The largest age group is persons 0 to 19 years of age, who account for 36.5 percent of the population. Median household income in 1994 was \$23,113. Nearly a third of the population lives below the poverty level.

The territory has two public hospitals: one on St. Thomas and one on St. Croix. The hospital on St. Thomas has two surgeons and two oncologists on staff. In St. Croix, there are four surgeons on staff at the hospital (however, three are retiring or leaving) and no oncologist. The territory has five health clinics in total.

### **Key Points**

- No research is being done on cancer in USVI, but mortality data indicate that cancer has been the second leading cause of death for the past 36 years. It has been the leading cause of death among males on St. Croix. Incidence of some of the common cancers (lung, breast, prostate, colon, uterine) appears to be rising.
- Breast cancer mortality has increased 134 percent among USVI women since 1982. This is compared with a 1.2 percent increase among women in the United States overall, and a 14.2 percent increase among African-American women.
- Cancer mortality in the continental United States is declining slowly, but this trend is not being observed in the USVI. Prostate cancer is the second leading cause of cancer death among men on the mainland, but it is the leading cause of cancer death in the USVI.
- Past efforts to establish a cancer registry program have been unsuccessful, principally for political reasons. In 1997, however, a grant from the CDC helped overcome some of the issues that blocked previous implementation. Last year, legislation was signed enabling the Registry and mandating electronic reporting from both of the hospitals and all the health clinics in the territory. To date, the Registry has been hampered by limited staffing, lack of compliance from the hospitals, and lack of onsite training that addresses scenarios specific to the territory.
- Currently, there are virtually no cancer treatment facilities in the territory. Nearly all patients have to leave the territory for treatment at a time when people want to be near families and loved ones. This situation causes a great deal of emotional stress and financial hardship.

### **MS. DEBBIE CHRISTOPHER**

#### **Key Points**

- The most vulnerable populations on St. Croix are men and women over age 50 and women aged 35 to 45 years, many of whom are minorities. The elderly, on very limited and mostly fixed incomes, and the uninsured and underinsured are at greatest risk.
- Larger numbers of Virgin Islanders are becoming educated about, and even screened for, cancer, but necessary followup, diagnostics, treatment, and rehabilitative services are unavailable.
- Competent, culturally sensitive logistical and emotional support throughout the care process is severely lacking. The USVI is comprised of diverse cultures. Outreach workers are few, and their messages must be tailored to the people of each culture. Health care providers need to update their knowledge of cancer care advances. They also must stop creating false hopes for their patients and incorporate cultural sensitivity into their care.
- Political considerations are preventing people from getting the care they desperately need. The closest location for continued care is 40 miles away by sea or air; travel costs are astronomical; and availability is very poor. Older residents sometimes must seek care three times per month, and many are on very limited incomes. One of the two oncologists on St. Thomas sees patients only sporadically and only through his private practice. Individuals sometimes make the 40-mile trip and return without seeing a doctor or receiving chemotherapy, which is not available on St. Croix.

- Many residents would rather die than seek medical attention. They feel there is no reason to be screened, since care is not available at home, and they are unwilling to leave their families. Fear and other barriers also keep people from seeking care.
- Federal funds, once received, are often commingled with local funds and may never reach local programs.

## **Recommendations**

- The USVI desperately needs help to link with existing networks to improve public awareness and outreach training, and to enable residents to receive cancer care in their own communities.

## **DR. WILLIAM FOGARTY**

### **Background**

The Juan F. Luis Hospital is the only hospital on St. Croix. It is a 140-bed facility with approximately 50 physicians on staff. It has a dialysis unit, a major trauma center, and a full-service blood bank. However, some blood must be obtained from the American Red Cross in Puerto Rico. Financial administration of the hospital has become semiautonomous from the government—i.e., the hospital can keep and disburse its revenues rather than having to put revenues in the government's general fund and then requesting disbursements needed to pay vendors. This change has been beneficial to hospital operations.

### **Key Points**

- The economy of St. Croix is declining. The island receives only minimal benefits of tourism, which is centered in St. John and St. Thomas. Per capita income is perilously low; even some government workers subsist on an annual income of \$10,500. Living expenses are extremely high; housing and food are very expensive. For example, a half-gallon of milk costs nearly \$3.00.
- Forty percent of the population has no health insurance. Physicians working at the hospital receive a small stipend for providing care to the indigent and supplement their incomes with private practice. Physicians on St. Croix are not wealthy.
- The hospital currently has no MRI, though a machine is said to be on the way. The island has only one dedicated mammography unit. There is neither a facility for performing chemotherapy infusions nor nurses trained to do chemotherapy or infusion therapy.
- The island also has no hematologist/oncologist; patients must travel to St. Thomas for oncology care. The round-trip airfare is \$170. A hydrofoil service that was less expensive has gone out of business. Round-trip airfare to Puerto Rico is \$250.
- St. Croix has no cytotechnologist; Dr. Fogarty screens all Pap smears and performs body fluid cytology.
- The medical staff of the hospital is aging; almost all of the 50 staff doctors are over age 50. In the next year, one-fifth (10) plan to retire or engage in other pursuits. The hospital has been unsuccessful in recruiting new doctors, since the government cannot afford to pay them. Similarly, the island had five surgeons; with attrition and retirement, that number will be reduced next month to a single surgeon who will be on call 24 hours a day.

## **MS. DOROTHY STRAUN**

### **Key Points**

- Insufficient public education is the major reason research results are not reaching patients. Most affected are indigent families, who have limited access to quality cancer care because of its high cost. Most are uninsured, even for basic health care.
- Cancer still carries a stigma in the Virgin Islands and contributes to denial of and secrecy about the disease.
- People affected by cancer need education to distinguish between sympathy (which is rejected as a sign of inadequacy) and support. Caregivers must empathize, not sympathize, with patients.
- Travel costs for diagnostic tests or cancer treatment can also include costs for food and lodging when it is not possible to return home the same day.
- Waiting for test results, particularly when the tests have been done on another island or in Puerto Rico, can be stressful. To reduce this problem, St. Croix needs a clinic to handle testing and uncomplicated cases.
- Churches and small community groups are important forums through which to communicate cancer information, since people in those settings have a common ground on which to interact from a position of mutual trust and respect.

### **Recommendations**

- Health providers and administrators must learn to communicate more effectively, and when necessary, at the educational level of the patient.
- In order to shape public policy, community resources must be marshaled to present a unified front to legislators concerning cancer prevention and control.
- Breast self-examination should be taught to girls in the 8<sup>th</sup>, 11<sup>th</sup>, and 12<sup>th</sup> grades. In addition to increasing their own awareness, the girls can share this information with their mothers.
- Greater effort must be made to encourage men to accept prostate cancer screening.

## **DISCUSSION—U.S. VIRGIN ISLANDS**

### **Key Points**

- Distance from care is a major issue in rural and remote areas such as those in Wyoming or other sparsely populated States in the United States, but at least it is possible to drive from one place to another. The situation in the Virgin Islands is more severe because it is geographically isolated.
- Spanish-speaking patients who need to leave USVI for treatment often choose to go to Puerto Rico; those who speak only English may choose to go to Miami if it is possible to do so. Since communication is so important in dealing with cancer patients, the language barrier is a major issue for USVI patients.
- The British Virgin Islands (BVI) faces similar, if not more severe, problems. The only hospital there is a 40-bed facility. Because St. Thomas is a short ride by ferry, BVI looks to the USVI for cancer and other health care. St. Croix, however, is isolated from the other Virgin Islands; it is 40 miles away from St. Thomas, across the Virgin Basin, which is up to 15,000 feet deep.

- Ms. Christopher indicated that with the help of investors, BVI is about to establish a major medical facility that may become the medical care center of the Caribbean. Importantly, considerable public and governmental will exists to improve health care in the BVI—which seems to be lacking in the USVI. She believes outside help is needed to spur progress in the USVI. It should be possible to establish networks, collaborative agreements, or other mechanisms to piggyback onto existing resources and infrastructure. In such collaborative efforts, St. Croix, though geographically distant from the other islands, should be an equal partner.
- The uninsured in St. Croix are eventually treated when admitted to the hospital from the emergency room or directly from a physician’s office. These patients tend to have late-stage disease. Dr. Fogarty observed that he has seen more invasive cervical cancer in 3 years in St. Croix than he did in 27 years of practice in Wyoming. Four members of the medical staff of 50 have or have had prostate cancer.
- St. Thomas is the seat of government for USVI. The hospital there is consistently better staffed and funded than the hospital on St. Croix.
- USVI has Medicare; Medicaid; the Women, Infants, and Children (WIC) program; Blue Cross/Blue Shield of the Virgin Islands (the government-sponsored program covering government employees and others); and United Healthcare. Federal Medicaid matching funds are inadequate for the population’s needs.

## **KENTUCKY**

### **Presenters**

**Mr. Greg Lawther**  
**Dr. Gilbert Friedell**  
**Dr. Wayne Tuckson**  
**Mr. Jarrett Mynear**  
**Ms. Loretta Farris**

### **MR. GREG LAWTHER**

#### **Key Points**

- Kentucky has high rates of cervical cancer incidence and mortality, especially parts of eastern Kentucky. These rates likely would be higher if not for the established screening program that now reaches almost 100,000 women annually. Mortality rates have begun to decline but are still too high.
- Breast cancer screening in the State did not begin in earnest until the early 1990s, following a significant infusion of new State funding for those efforts. Breast cancer mortality approximates the national average, but screening rates, especially in low-income and older women, are unacceptably low. With added Federal and State funding in the past decade, the screening program now reaches approximately 17,000 women per year. Since the program’s initiation, more than 100,000 screening mammograms have been performed, and more than 700 cases of breast cancer have been detected. Of these, 60 percent have been detected at an early stage of disease.
- Kentucky has among the highest lung cancer incidence and mortality in the Nation. In the last several years, however, the State has progressed from having no tobacco control program at all to having a nearly \$4 million program with four staff. The Governor has challenged the State to reduce youth smoking; this support is very important. It is hoped that a robust program in this area will be well established by the end of the Governor’s term in office.

- These successes have been important, albeit incremental and insufficient to meet the need. For example, breast and cervical cancer screening is only reaching about 20 percent of eligible uninsured and underinsured women.
- The uninsured and underinsured are the primary underserved populations. As much as 25 percent of the population, or approximately one million people, is uninsured or underinsured. With regard to breast and cervical cancer screening, poor women, those between ages 50 and 64 years, Appalachian women, and the growing Latina population are all underserved. No one approach will be successful in reaching all of them.
- The State is still working to find ways to get some of these women in for screening. The Health Department has tried to take advantage of the opportunities presented when women, particularly those of childbearing age, come to local health departments for other reasons. It has been more difficult to get older women to come in for screening. The body of knowledge amassed from screening programs in other States is invaluable, but screening must be tailored to specific target populations.
- It is likely to be more difficult to reach men for prostate and colorectal cancer screening, since they do not regularly come to local health departments for other services.
- Individuals, their providers, and the health care system must work together to encourage and facilitate behavior change. Education is the key to changing public and provider behavior, and the system must be modified to support these behaviors. In addition to education, policymaking, planning, and collaboration are essential.
- Lack of funds and of access to state-of-the art care are among the barriers keeping people in Kentucky from receiving the most appropriate treatment. People in rural areas often cannot or will not go to the metropolitan areas to receive care, even though they may receive better care in those locations.
- Even highly educated people with resources are intimidated by the choices that must be made following a cancer diagnosis. Mr. Lawther related that his mother was virtually unable to cope with such decisions after his father's lymphoma diagnosis.
- Care can be improved at the local level by building local capacity and support. In Kentucky, breast and cervical cancer coalitions exist across the State. One of these is a partnership in Louisville that got a mobile mammography unit and van donated for use in the city's African-American community. In addition, Providers Practice Prevention is a program that has been very successful in educating physicians about breast and cervical screening.
- Kentucky still lacks necessary funding to address the needs of women in the State. The Medicaid funds that became available as a result of the Breast and Cervical Cancer Treatment Act will help only a fraction of the women served by the screening program.
- The quality of mammography performed statewide is too widely varied and reflects serious inconsistencies in the practice of radiology in the State.

## **DR. GILBERT FRIEDEL**

### **Background**

The [white] Appalachian population is rural, poor, and poorly literate. Its problems with cancer are similar to those of minority populations in other parts of the country. Lung and cervical cancer incidence data indicate that both Appalachian and African-American populations in Kentucky have rates in excess of those of white populations in other regions. However, the cervical cancer survival rate of African-American women is lower than that of Appalachian women; this disparity may be due to differences in race or in treatment.

The Kentucky Cancer Program (KCP), formed in 1983, is a joint enterprise between the University of Louisville and the University of Kentucky in Lexington. The KCP now has 13 regional outreach offices across the State, each of which deals with 1 or 2 of 15 district cancer councils. These councils provide both public and professional education. KCP also includes the Cancer Registry and the NCI-supported Cancer Information Service covering the six States of the Mid-South region.

A 2-year Governor's Task Force on Breast Cancer has been formed; it has developed a Kentucky Action Plan and a self-study kit for primary care providers on breast and cervical cancer screening entitled Providers Practice Prevention. The kit has been widely adopted and utilized.

The Kentucky Homeplace Program is funded by the State legislature. Among other activities, it provides payment and training to Community Health Advisors who work principally in Appalachian Kentucky to amplify early detection messages and help members of the target population reach service points.

### **Key Points**

- The medically underserved includes individuals and populations for whom high-quality health care services are not available and/or accessible and/or utilized. In Kentucky, some areas do not have adequate cancer care resources. In other areas, people have access to services but do not use them.
- It is imperative to have a high-quality cancer registry in every State. Effective cancer control is impossible at the local level without a registry.
- Many of the cancer care barriers facing the population of Kentucky are similar to those discussed by others at the meeting. However, literacy is a particular problem in the State.
- If the problems are in the community, the solutions are in the community and must be implemented *by* the community. The "top-down" approach does not work in dealing with real people with real problems.
- Educational level is a surrogate measure of socioeconomic status but also reflects literacy levels. Providers need to query patients about highest grade of formal schooling achieved. It has been suggested to the Joint Commission on Accreditation of Health Organizations (JCAHO) that this information should be a required part of the initial hospitalization record.
- Kentucky is conducting a pilot project to develop guidelines for breast cancer care.

### **Recommendations**

- Additional research is needed to determine the actual impact of race and ethnicity on cancer care and how these factors interrelate with or are separate from socioeconomic status.
- State cancer registries should receive additional funding to enable them to collect longitudinal data and more complete treatment data. Registries not currently part of the SEER system also should be funded to gather these data.
- Registry process and outcome data must be studied in relation to geographic and socioeconomic factors and the availability, accessibility, and utilization of services.
- State mammography registries are needed to improve quality control of this service in both the public and private sectors. The FDA requires radiologists to collect these data, but the data are never shared, and it is unknown whether they are used to improve services.
- Professional and public education about breast and cervical cancer screening must be strengthened. In particular, public education is needed to encourage screening among older women. Older women are not being screened adequately.

- Steps must be taken to ensure that older cancer patients receive appropriate care. Evidence suggests that older women in particular are not receiving all medically indicated care.
- Multidisciplinary care for cancer must be increased and should begin at diagnosis. In addition to surgeons and medical and radiation oncologists, the team should include oncology nurses and psychosocial support professionals.
- All cancer patients should have access to second opinions.
- Patient Navigator programs should be more widely available.

## **DR. WAYNE TUCKSON**

### **Key Points**

- There often is a difference between what is perceived to be a problem and reality. In health-related issues, both communities and health care providers can have difficulty discerning the real nature and magnitude of a problem.
- Residents in western Jefferson County, Kentucky, which includes Louisville, believed that they had a disproportionate cancer burden compared with residents in other areas of the county. This belief was based on observations of an increased number of their neighbors dying from cancer and the proximity of a number of chemical plants polluting the air in the area. The residents of the area are primarily African-American and poor. When 3 years' worth of cancer incidence, mortality, and other data from this area were examined, it was found that these residents' cancer incidence was only slightly different from that of residents of the eastern part of the county, but they had significantly higher cancer mortality. Further examination of the data revealed that the western county residents also had the lowest education and income levels and were diagnosed at later stages of disease for almost every type of cancer.
- A countywide followup telephone survey also revealed that residents on the west side of the county had fewer regular physician visits compared to those in the eastern county, were less likely to have a private physician, and had more emergency room or clinic visits. In addition, residents on the western side of the county tended to smoke more, be overweight, have unhealthy diets, and have lower screening utilization except for prostate cancer screening.
- This information pointed to several problems: lack of awareness of the association of behavior/lifestyle with cancer development; disassociation from the health care system; poor access to care due to location and transportation issues; disparate quality of care; and lack of physician-patient trust. In addition, though a number of cancer-related community, public, private, and governmental efforts were underway, they often worked at cross-purposes or even in competition.
- When patients were diagnosed, they had no guarantee of being treated, and if they were treated, there was concern about the quality of treatment they would receive. This situation was a strong disincentive to screening.
- Residents of the area also were frustrated because access and environmental issues in the county had been studied repeatedly, with no apparent result.
- Likewise, funds appropriated for educational activities sometimes do not result in services to people, particularly in the predominantly African-American, western part of the county; this is unacceptable.
- To raise the "health IQ" of the populace, a partnership was established with Kentucky Educational Television. A television show has been developed in which health issues are discussed in a simple and straightforward manner. Videos have been developed and placed in community centers to create a health care library. Annual symposia on cancer feature community representatives and outside



speakers to deliver information (e.g., how to eat in a healthy manner); these have been very popular. Health fairs in various communities introduce health topics and encourage participation.

## **Recommendations**

- To make the most efficient use of funds and the available time of the target audience, community, public, private, and governmental health promotion activities should be coordinated. Such coordination will allow a greater percentage of resources to be used for support services needed by the population.
- It is essential that people who are screened for cancer receive prompt, appropriate care if cancer is diagnosed. Funding must be available for treatment.
- Research on the causes and incidence of cancer in specific communities must include provision for treatment.
- The health care community is itself a barrier to better care; health care providers must be educated so that patients do not avoid seeking care.

## **MS. LORETTA FARRIS**

### **Background**

Ms. Farris is a retiree from the United States Air Force. Until 2 years ago, she had CHAMPUS military insurance, for which the carrier was Blue Cross/Blue Shield. She never had problems with any provider accepting assignment. More recently, she has TriCare, the military managed care plan, and has had continual problems with: providers who will not accept assignment, claims denial due to provider coding errors, and pressure for payment that she indicates borders on harassment.

Ms. Farris has had four cancer diagnoses since 1986 and is still living with active disease. Throughout these experiences, few if any support services were available in her hometown of Carlisle, Kentucky. In 1997, a Breast Cancer Coalition was formed in Nicholas County. The Coalition includes survivors, health care providers, professionals, and others from the community. It organizes and participates in community cancer awareness and education, as well as other events. The community now has numerous support groups and services. Ms. Farris noted that breast and prostate cancer now are being discussed openly in the community, a phenomenon she would not previously have imagined.

The Coalition now has funding, but in its first 2 years, it was entirely a volunteer effort. Ms. Farris strongly encourages communities to involve survivors in cancer control efforts.

## **MR. JARRETT MYNEAR**

### **Background**

Jarrett Myneer, aged 11 ½, has been diagnosed with cancer six times in the past 9 years. He has received treatment at the Mayo Clinic (Rochester, Minnesota), the Fred Hutchinson Cancer Research Center (Seattle, Washington), and the University of Kentucky Children's Hospital (Lexington).

### **Key Points**

- Pediatric cancer patients and their families need a system that meets *all* the needs of patients and families, not just medical needs. Many families would be better able to cope with the diagnoses, treatments, and other aspects of cancer care if they had a good psychological support system. Some

families break apart due to the stress of long hospitalizations and the uncertainty of their children's illnesses. To help families communicate with their doctors, Jarrett's mother and some of the physicians have established an arrangement whereby volunteers watch the patients so that parents can meet with the doctors.

- Few families with private insurance have coverage for services to help them cope with the stresses cancer brings to families, particularly those with siblings. Such services also are not available to families in Kentucky with public insurance. In addition to health worries, cancer brings financial and emotional stresses.
- At the University of Kentucky Children's Hospital, over 55 percent of cancer patients are on Medicaid. Some of the State's Medicaid coverage policies are detrimental to the best care for pediatric cancer patients. For example, hydration fluids are not covered; when patients need such care, the hospital must cover the cost. Similarly, Medicaid pays for only one chemotherapy treatment per day, although many patients require more than one treatment on some days. Though the other treatments are given as they should be, the payment comes from the pool of money used to run and staff the Pediatric Oncology department. This situation has adversely affected staffing in the Pediatric Oncology unit.
- It does not seem right that Kentucky's Medicaid pays for preventive care visits (e.g., vaccines and their administration) but covers only one chemotherapy and its administration per day, regardless of what actually is needed to bring a child with cancer back to health. Low Medicaid payments are the single biggest threat to pediatric oncology and equal care for all oncology patients in Kentucky—as well as in other States with high rates of public assistance. Federal guidelines are needed to resolve these issues.
- Diagnosis for rural teens with cancer is often delayed, and they may not receive followup care or testing for symptoms that doctors cannot explain. In addition, even when teens are diagnosed, they may be sent to local oncologists or treated by primary care physicians instead of being sent to the cities for pediatric oncology care and possible clinical trial participation. Jarrett recounted the case of a friend whose symptoms were misdiagnosed for months, even after he had developed a lump on his chest and a CT scan showed a large lung tumor. Some of the symptoms were attributed to puberty. Finally, the friend's parents took him to the University of Kentucky Medical Center, where he was diagnosed with advanced Ewing's sarcoma; he has since died.
- Jarrett indicated that he is planning to write a book on his cancer experience, with facts about cancer and his views on coping with cancer, talking with doctors, and things patients should know about their treatment.

## **Recommendations**

- Professionals who help deal with the stresses of cancer should be available to all families regardless of income level or type of insurance. Oncologists are fully occupied addressing patients' medical issues.
- Every child and adult in this country deserves equal care and the best care, no matter what the family can or cannot afford. Cancer patients deserve the best that money can buy, and should not find themselves in a situation in which doctors are forced to decide between medicines for the underinsured and having the money to pay for staff to help administer those medicines and care for children with cancer.
- Where you live in a State should not be a factor in how quickly you are diagnosed and provided with cutting-edge treatment and choices.

## DISCUSSION—STATE OF KENTUCKY

### Key Points

- When he was 9½ years old and undergoing a bone marrow transplant, Jarrett Mynear noticed that many of his fellow patients in the Pediatric Oncology unit had few visitors and toys—most likely because they were from out of state or distant parts of Kentucky. As soon as he was well enough, he started Jarrett’s Joy Cart, sharing toys he had received as gifts from visitors. Jarrett counts this as perhaps his most positive cancer-related experience. His most negative experience occurred when he received treatment for approximately 6 months in Seattle, Washington, and could see his father and sister only twice a month.
- The Providers Practice Prevention program is a self-study kit based on a five-part video developed with CDC funding by the Kentucky Cancer Program. It describes the best methodology for conducting breast and cervical cancer screening, with particular emphasis on screening older women. The kit is advertised in medical publications and also has been promoted by medical malpractice insurance companies that operate in Kentucky. Participants get continuing medical education credit and a 5 percent reduction in their malpractice insurance premiums for the year during which they use the kit. To date, 878 physicians have requested the kit; of these, 43 percent participated in the program. The kit has proven a highly successful method of accomplishing professional education and does not require physicians to go to meetings to obtain information. It has been expanded to include a program for nurse practitioners and physician assistants. Of the more than 500 who have ordered the kits, 66 percent have completed the program. The CDC has decided to make the kit available nationally.
- Currently, State cancer screening programs (e.g., breast, cervix) appear to be dependent largely on the availability of Federal funding. To address cancer issues particular to each State (e.g., lung cancer in Kentucky), each State will need to appropriate its own funds to develop and implement screening efforts.
- Categorical funding for screening and other cancer control efforts is at odds with a more beneficial “whole person” approach to cancer control and overall health. In addition to more funding, States need more flexibility in how they use categorical funds.
- In determining funding targets and levels, it tends to be true that “the squeaky wheel gets the grease.” To improve funding for cancer screening and cancer control, it will be necessary to raise public awareness of cancer health issues. However, to avoid competition among advocates, researchers, and program personnel for various cancers, we need a national cancer plan for the entire National Cancer Program that has a unified voice and global view of cancer research and care needs.
- Tobacco-producing States have been hindered significantly in their efforts to secure funding for smoking prevention. Few can deny, however, that youth should be discouraged from smoking, and youth tobacco use prevention may prove to be the common ground on which the public health community, the public, and those dependent on tobacco income can agree.
- The economic tie to tobacco is strong. When faced with the closing of a Louisville tobacco factory and concomitant job loss, Kentucky opted to keep the factory open. This sends a mixed message to youth. At some point, government, industry, and the public have to be strong enough to suffer the temporary economic consequences of ceasing tobacco production and processing. Thus far, people have been unwilling to take this step.
- A good database is essential to determining the effects of various demographic and socioeconomic factors in disease incidence and outcome. In comparing data on various populations, minority population statistics should be compared to the lowest 10 to 15 percent of the white population.

Comparing against the entire white population skews the comparisons in ways that are likely to obscure the real disparities.

- Currently, community research typically makes little or no provision for continuing successful interventions beyond the grant period. It was suggested that addressing this problem could involve several avenues: couching interventions within an overall approach that takes the whole person into account; requiring that interventions provide for screening and treatment, as needed, when problems are identified; and providing minimal continuing funding and ongoing technical assistance, as needed, to help community coalitions remain intact.
- Medicaid reimbursement for chemotherapy should be based more realistically on patient need. Likewise, reimbursement for prosthetics should be realistic in terms of the actual cost of prostheses and the frequency with which they must be replaced—particularly for pediatric patients.

## **MISSISSIPPI**

### **Presenters**

**Ms. Melody Fortune**

**Ms. Nedra Lisovicz**

**Mr. Robert Teague**

**Ms. Margaret Bowen-Jones**

**Ms. Beverly Diamond**

### **MS. MELODY FORTUNE**

#### **Background**

Due to very limited funding, most of the cancer-related efforts of the Mississippi Department of Health center on the Breast and Cervical Cancer Screening Program funded by the CDC. Moreover, Mississippi was one of the last States to implement a CDC-funded screening program because until 2 years ago, the State did not appropriate the matching funds needed to secure the Federal funds. To date, the program has enrolled just over 2,700 women. Sixteen cases of breast cancer have been detected; all of these women have received treatment, even though no treatment funding is available through the Program.

In the year 2000, some 2,000 new cases of invasive breast cancer will have been diagnosed in the State, and about 400 women will die from the disease. White and nonwhite (nearly all of whom are African-American) women have equivalent incidence and mortality rates from breast cancer. Disparities in screening rates exist between white and nonwhite women.

Nonwhite women in Mississippi have almost twice the cervical cancer mortality rate of white women in the State. The difference in screening rates is small, but repeat screening rates are lower for both groups.

Approximately 1 percent of the State population is Hispanic.

#### **Key Points**

- As in other States, barriers to screening and care are related to low socioeconomic status, transportation problems, access to health care facilities, belief systems, provider education, public awareness, and health care costs.
- The cost of treating early breast cancer is one-third to one-half the cost of treating late-stage disease.

- An article in the *American Journal of Epidemiology* indicates that exposure to secondhand smoke at the rate of 1 hour or more per day for 1 year can almost triple a woman's breast cancer risk.

## **MS. NEDRA LISOVICZ**

### **Key Points**

- So-called hard-to-reach populations are not really hard to reach. In fact, they are waiting to be reached. They are only hard to reach for academics, health care providers, and service providers.
- Community Health Workers (CHWs) are persons indigenous to a community who provide informal, community-based health-related services, establishing vital links between their peers and health care professionals. CHWs educate individuals in communities, facilitate access to needed services, educate providers in health service systems, and craft systems that are most responsive to their individual communities. They are catalysts for change, and they are the ones who speak like, look like, act like, and understand the culture of the people in their communities. These characteristics enable them to provide education in a language and form to which community members can relate.
- The disconnect between research and practice centers on the lack of sustainability of Community Health Worker programs. When those programs come and go in 5-year cycles, the community eventually becomes resistant to working with new programs or accepting health-promoting messages and interventions.
- Even when services are accessible in the community, residents perceive a lack of access because they are unable to navigate the programs, and most programs do not provide case managers to assist them with access issues.
- Mississippi suffers from a lack of awareness of patients' rights and a lack of health care providers, particularly in the Delta region.
- The State recently received an NCI Special Populations Network grant that will work with CHWs to get breast and cervical cancer information out to the community. Though the State already is positioning itself for the second round of funding, no guarantee exists that the program will continue after the initial 5-year grant period.
- Key barriers to the most appropriate care include transportation, lack of providers, language or cultural barriers, and perceived access barriers. The underserved are those, in both urban and rural areas, with low socioeconomic status and education. They are entrenched in traditionalism, both culturally and religiously. Many do not seek treatment, believing that if God did not want them to have cancer, they would not have it.

### **Recommendations**

- Sustained funding for Community Health Worker programs is needed.
- Incentives are needed to encourage health care providers to locate and stay in underserved areas.

## **MR. ROBERT TEAGUE**

### **Background**

Mr. Teague, a psychiatric social worker, has lost his father, two uncles, and two first cousins to prostate cancer. He is a 3-year survivor of the disease. He and his urologist (also a prostate cancer survivor) formed a support group that later was chartered as a local chapter of US TOO! International. In addition, they started a weekly, free screening program sponsored by women from local churches. The program

tapped the power of women to dictate the health care patterns of family members. Videos featuring local people help communicate key information and overcome many of the barriers residents have in interacting with the health care system.

The prostate cancer screening program and the support group also provide opportunities to discuss wellness in general. Mr. Teague counsels men who are diagnosed, and they are subsequently followed by the support group, which includes their family members and significant others, particularly women. Both programs have been in operation for 2 years.

## **MS. MARGARET BOWEN-JONES**

### **Background**

Ms. Bowen-Jones lost her mother and all her mother's five siblings to cancer. She was diagnosed with breast cancer 7 years ago, after a lump previously determined to be benign was found to be cancerous. She was treated with lumpectomy and radiation. She subsequently needed chemotherapy. She had the treatment, continuing to work as a nurse throughout. Between her own and her husband's insurance, she was able to pay for her care.

Ms. Bowen-Jones indicated that her faith guided her in every aspect of her treatment. She has written a book, *From Darkness to Light*, to describe her experience and help others understand that a cancer diagnosis is not a death sentence.

### **Key Points**

- Family members and friends must be encouraged to be screened and to conduct breast self-examinations.
- Many fear screening because they know they cannot afford to pay for treatment.

### **Recommendation**

- Survivor registries are needed to demonstrate that cancer is not a death sentence.

## **MS. BEVERLY DIAMOND**

### **Background**

Ms. Diamond is a 5-year survivor of ovarian cancer. She had been feeling ill and went to four or five doctors before she found one who indicated that she had fibroid tumors that could be cancerous. She had surgery and early-stage cancer was found beneath her ovaries. Ms. Diamond subsequently received 6 months of chemotherapy. She indicated that this was an exceedingly difficult time, made more difficult by trying to work while feeling weak and tired. She was insured throughout her treatment and experienced no insurance-related problems.

### **Recommendation**

- Working while in chemotherapy is extremely difficult. Some type of disability coverage should be available for chemotherapy patients for the duration of their treatment.

## **DISCUSSION—STATE OF MISSISSIPPI**

## **Key Points**

- A program to encourage medical students to practice in underserved areas is more likely to be successful if the students have some experience in underserved areas, if they have compatible cultural backgrounds with the community in which they will live, and if they are in the community for at least 5 years. The Delta is a very hard place to live in, and some providers who have attempted to practice in the area have left because they could not sustain a personal and family life in the community. Ms. Lisovicz observed that matching providers and communities culturally is essential because if the provider hates life in the community, the patients certainly will know it. It was noted that Mississippi has used many foreign medical graduates (so-called J-1 Program doctors), but the cultural incompatibility has been problematic. Other doctors who are more culturally compatible have been recruited through the National Health Service Corps, but retaining them after their period of obligation ends has been difficult.
- Ms. Bowen-Jones indicated that she currently is seeking a publisher for her book.
- Some of the counties in the Delta area are among the poorest in the country. It is a predominantly rural area, with farming the major vocation three seasons of the year. In the cycle of planting and harvesting, there are times when residents have no income at all. Gambling casinos are being introduced to the area, but the local residents are only able to get minimum-wage jobs at these casinos. The majority of the population is African-American, although the Appalachian region is home to many poor whites. These populations have approximately equivalent breast cancer death rates; the common factor is poverty.
- Low socioeconomics and low education together create an apathetic state of mind concerning the possibility of survival if cancer is diagnosed. In addition, women in this population often communicate to other women cultural beliefs that thwart early detection. The Deep South Network will be trying to reach women with early detection messages so that they will feel empowered to seek care and believe that cancer is survivable. CHWs are a necessary component of the program since they can help women access Medicaid or other benefits for which they are eligible.
- Several speakers expressed the power of faith in helping people deal with cancer and the fact that spiritual belief does not exclude interaction with the health care system. The Witness Project, operating in several States, was cited as an effective mechanism for involving the faith community in cancer awareness and cancer control.

## **NORTH CAROLINA**

### **Presenters**

**Dr. Deborah Porterfield**

**Dr. Keith Wailoo**

**Dr. Lorna Harris**

**Ms. Elizabeth Owle Wiggins**

**Ms. Deirdre Mack**

### **DR. DEBORAH PORTERFIELD**

#### **Background**

Census data from 1995 indicated that 917,000 people in North Carolina were uninsured, and this number continues to grow. The State Health Department operates two programs to address early detection of cancer in uninsured populations. The Breast and Cervical Cancer Screening Program is administered through local health departments and reaches all 100 counties in the State. In Fiscal Year 2000, more than

9,000 mammograms and more than 7,000 Pap smears were provided through the Program. Yet analysis of census data for the primary target population—women aged 50 to 64 years with incomes at 200 percent of poverty level—reveals that only 3.6 percent of eligible women are being reached. In the coming year, the Program will be expanded to include rural health centers, community health centers, and other providers.

In 1999, a pilot colorectal cancer screening program was initiated in ten local health departments. Close to 500 patients have been screened with fecal occult blood tests (FOBTs). After the program has received a process evaluation, it may be expanded to other health departments.

Cancer treatment for the uninsured is a goal under the State plan. The North Carolina Cancer Control Program was established in 1945 and is entirely State funded. Its current budget is about \$3 million. Eligible patients are residents who are uninsured or underinsured, are at or below 115 percent of the poverty level, and have at least an estimated 25 percent chance of 5-year survival. The Program pays for diagnostic services for patients with suspected cancer, and for treatment services for those diagnosed with cancer. Fifteen percent of the budget is paid directly to contracted cervical dysplasia and breast clinics; 65 percent is spent on provider and hospital reimbursements.

In Fiscal Year 2000, the Cancer Control Program saw 1,507 patients for diagnostic procedures and 556 patients for cancer treatment. Of the patients receiving cancer treatment, 42 percent were 21 to 34 years of age. Analyses are now being conducted to determine the effectiveness and reach of the program and to assess the relationship between insurance status and stage of diagnosis.

### **Key Points**

- Analyses to date suggest that patients in North Carolina with Medicaid coverage are more likely to be diagnosed with late-stage cancer than those with no insurance at all.
- The Health Department will be seeking additional funding for the Breast and Cervical Cancer Screening Program and additional funding to extend eligibility for the Cancer Control Program to people at 200 percent of poverty. Greater support is needed for community programs designed to strengthen and support safety net providers of all types. The Health Department also is working with Medicaid to implement the recent Federal legislation providing cancer treatment for women diagnosed through the Breast and Cervical Cancer Screening Program.
- Needs at the State level include methods to overcome screening barriers in the uninsured population, implementation of evidence-based strategies at the State and local levels, better descriptive information about the population to inform resource targeting, and a study of uninsured cancer patients designed to better understand their out-of-pocket costs and outcomes—with the goal of developing evidence to support greater funding for earlier detection.

## **DR. KEITH WAILOO**

### **Background**

Dr. Wailoo is a historian who currently is writing a book on the history of cancer that focuses, in part, on the history of race relative to cancer in America.

### **Key Points**

- Through most of the first half of the 20<sup>th</sup> century, cancer was considered to be a disease affecting primarily urban dwellers and whites. Public discussions about cancer focused on its impact on middle- and upper class whites. These perceptions stemmed in large measure from the life insurance data used to assess causes of mortality. These data had serious limitations, since most of the insurance



business in those years was done in Northeast urban areas and did not reflect the conditions or experiences of the predominantly African-American population of the rural South. As a result, this population and geographic region were essentially ignored in terms of cancer, though their omission in cancer statistics did not escape the notice of researchers. It was noted that rural whites were more likely to be diagnosed as having died from cancer than were African Americans. Current data collection practices continue to have similar limitations.

- Thinking about cancer began to change mid-century due to several factors. African Americans were moving to the cities, where they were more likely to be diagnosed with cancer (and diagnosed earlier), thereby changing the estimated cancer rates. The population was aging, also affecting cancer incidence rates. New diagnostic tests, such as the Pap smear, were beginning to be used widely. In addition, different types of data were being collected at hospitals, including hospitals in the South. All of these factors began to change the picture of race, region, and cancer.
- By the 1950s and 1960s, it was realized that cancer was not a single disease and that different types of cancer affect some population groups more than they affect others. Public focus centered on lung and cervical cancers. Available data suggested—and it was generally believed—that African Americans had half the lung cancer rate of whites and were likely less susceptible to the disease. Cervical cancer was believed to be more common among African Americans than among Caucasians.
- Whereas public images and messages encouraged white women to be open about cancer, black women with cervical cancer were stigmatized and blamed both by researchers and by a medical community that claimed that black women had higher cervical cancer rates because they had intercourse earlier in life, married earlier, and had sex with uncircumcised men.
- The 1960s through 1980s saw an important shift toward thinking about broader issues in cancer and race/ethnicity. Poverty, socioeconomic status, and environmental and social factors helped explain observed differences. However, communication about cancer lagged behind this more enlightened thinking. “Illness narratives” (stories about personal cancer experiences through which cancer detection messages were communicated) in mainstream media still focused on white women. There were very few images of men and fewer of nonwhites. Not until the late 1960s and 1970s did such narratives of African Americans begin to appear, in both mainstream and specialized publications (e.g., *Ebony* and *Essence* magazines). Thus, it is only in relatively recent years that cancer has been discussed within African-American and other minority communities.

## **Recommendations**

- Much is said about patients’ behavior (e.g., misunderstandings, fatalism, cultural beliefs) and barriers to cancer awareness, but cancer communication is a broader problem that must be addressed, in part, by correcting physicians’ and cancer professionals’ own misunderstandings about cancer and the way they communicate cancer information.
- Culturally specific illness narratives should be disseminated to help describe to all populations the complexities of the cancer experience, including both survival and loss. Hidden messages in the media should be identified.

## **DR. LORNA HARRIS**

### **Background**

The Historical Black College and University (HBCU) Medicaid Alliance is a partnership of four HBCUs; the State Offices of Minority Health, Rural Health, and Medical Assistance; and the Kate B. Reynolds Foundation, a charitable trust. The goal of the partnership is to improve the African-American community’s access to Medicaid services in North Carolina.

The North Carolina Comprehensive Breast and Cervical Cancer Control Program includes more than 70 public and private agencies that endeavor to increase screening, early detection, and followup care among low-income and high-risk women.

The North Carolina Advisory Committee on Cancer Control and Coordination is a policy and advisory group to the State legislature. The Promoting Health in the African-American Communities Project is a 7-year health promotion project in which church ushers serve as health advocates, similar to Community Health Workers in Mississippi.

## **Key Points**

- Cancer disproportionately affects minority communities in North Carolina; it is the leading cause of death in these populations. Major contributors to cancer care disparities for minorities in the State have been identified. Lifestyle contributors include high-fat and poorly balanced diets, lack of exercise, tobacco use, and the use of alcohol and other drugs. Access issues are related to poverty, lack of insurance or underinsurance, distrust of the health care system, and lack of transportation in rural areas. These issues are complicated by racism, stress, cultural beliefs and practices, and environmental hazards—both in the community and the workplace.
- Confusion exists in North Carolina minority populations as to what types of cancer screening are recommended for various age groups. Many women have now heard of mammograms but do not know when to begin having them. Many poor women have been reached with cancer prevention services through family planning clinics. However, women in their forties and fifties, who may no longer need birth control services, visit these clinics less regularly. Their medical services become more focused on chronic conditions such as hypertension and diabetes. Unless patients request cancer screening services, no one provider takes responsibility for arranging referrals for screening. Thus, although older women remain in the public health system, ensuring that they receive screening is more difficult.
- Medicare and Medicaid recipients have become part of the HMO care system. They often do not understand the concept of a primary care provider and how to manage the system to receive needed cancer screening. Medicaid is widely perceived as an illness service, and recipients hesitate to seek preventive services through the program.
- In addition, many older recipients believe that services are time limited and that benefits can be used up. Indigent, minority, and other underserved populations also do not understand that the best care may be available through clinical trials or that they can access trials through Medicaid and Medicare.
- Provider attitudes continue to be a barrier to care for minority and indigent clients who perceive that they are not receiving care and information equivalent to that provided private patients. This perception creates distrust between the client and provider.
- Participants in State Welfare-to-Work programs indicated that there often is a gap between when Medicaid eligibility is terminated and when employer health benefits begin, leaving them with no coverage at all.
- Medicaid recipients still have difficulties finding providers who accept Medicaid patients, and waits for appointments and services can be long.
- Some of these barriers can be overcome by:
  - Educating members of the minority community in both formal and informal settings
  - Clarifying screening recommendations

- Implementing culturally based media education campaigns
- Working with State agencies to improve the transition from Medicaid to private insurance
- Eliminating deductibles for preventive care and early detection services
- Eliminating limitations based on preexisting conditions
- Educating health care providers on primary and secondary risk factors for cancer in minority populations and screening followup routines
- Supporting and involving grassroots and other organizations that can design programs that will be effective with underserved populations in the State.

## **MS. ELIZABETH OWLE WIGGINS**

### **Background**

The Cherokee Women's Wellness Center offers breast and cervical cancer screening to women of the Eastern Band of Cherokee Indians, the only North Carolina tribe with both Federal and State recognition. Approximately 12,000 members live on the Qualla Boundary, a land area of more than 56,000 acres directly adjacent to the Great Smoky Mountains National Park. Average per capita income is slightly more than \$15,000, which is 60 percent of the national average and 65 percent of the State average. Approximately 34 percent live in poverty.

The Indian Health Service (IHS) hospital is the primary source of health care. Because the population of the tribe is growing, but funding for health services is dropping, some services, supplies, and drugs are becoming unavailable. The IHS hospital has the only no-cost mammography services available to tribal members; this level of capacity (one mammography machine and one technician) is insufficient to meet population needs.

Similarly, insufficient capacity exists to perform cervical cancer screening for tribal women. Last year, 49 percent of all cancers detected in the population were cancers of the cervix or uterus.

### **Key Points**

- Like other tribes of American Indians and Alaska Natives, the Eastern Band has long experienced lower health status than other Americans and is disproportionately affected by chronic diseases such as diabetes. Factors contributing to American Indian health disparities include culture, race, access to care, and socioeconomic status.
- It is well documented that cancer is the second leading cause of death for American Indians and that they have the poorest survival rate of any racial group. Moreover, survival rates may be underestimated due to misclassification of American Indians in State and national statistics.
- In the view of the Cherokee Cancer Support Group, the only disconnect between research findings and cancer care is economic. Most believe their postdiagnosis care has been adequate, but many are struggling to pay for medications that are not available at the IHS hospital. Some expressed concern that their diagnoses may have been delayed due to access issues or provider reluctance to make referrals outside the IHS system.
- Fatalism among the Eastern Band may be keeping people from seeking screening services. Mistrust of a cure may likewise keep people from screening or from seeking care for symptoms. Many believe

it is better not knowing if cancer is present than having a confirmed diagnosis. This fear may result in late diagnosis and contribute to increased mortality.

- Identified needs include increased education about cancer care, cancer treatment, and survival, as well as emphasis on early detection. Lay health advisors or community outreach workers are needed to spread these messages to the community.
- There is a significant need for followup care within the IHS community. Currently, patients are referred outside the system to providers unfamiliar with the patient, the culture, and the language. Patients feel disconnected and alone and do not understand how or with whom to reconnect within the local system. Case managers or advocates are needed to ease this transition.
- The emotional trauma of cancer for the patient and family may leave them unable to navigate the health system appropriately. The stoic nature of American Indians is often misunderstood as apathy or ignorance.
- American Indians are highly diverse and have widely varied needs; it is impossible to generalize cancer research findings to all tribes. Greater efforts should be made to evaluate the need for and efficacy of various cancer programs at individual tribal levels. The Native American community deserves and desires access to the most up-to-date cancer interventions and resources.
- The Eastern Band continues to be affected by all of the quality-of-life issues that are rooted in economic adversity and poor social conditions. Like other minorities who are socioeconomically disadvantaged, the tribe has higher rates of behavioral risk factors for cancer, including obesity, sedentary lifestyle, and tobacco and alcohol use. A painful history of disenfranchisement has left people with a feeling of powerlessness, poor self-esteem, lack of social support, and chronic stress. For many, daily survival takes precedence over such considerations as appropriate cancer screening. It is critical to acknowledge the interrelationship of these factors with health, disease, and disparities.

## **MS. DEIRDRE MACK**

### **Background**

Ms. Mack is a 4-year survivor of breast cancer. She is the sole support of her daughter. She discovered a lump in her left breast and was diagnosed just as she was about to lose her health insurance. She was able to secure a job at a bank that offered health benefits, although her cancer care was not fully covered because she could only afford premiums for the least expensive policy.

After surgery, Ms. Mack underwent both chemotherapy and radiation therapy. She was very ill from the treatment and lost a great deal of weight. She continued to work throughout her treatment because she had not accumulated any sick leave or vacation time on the new job and was afraid of losing her job if she took time off. Her mother assisted in caring for her daughter while she was in treatment.

Ms. Mack's experience spurred her to become involved in cancer advocacy. She has become involved with the Susan G. Komen Foundation, serving as her employer's team captain for the local Race for the Cure. In addition, she has been active in awareness activities with her church and in her community.

Ms. Mack observed that her breast cancer experience has been both a source of great fear and a blessing.

## **DISCUSSION—STATE OF NORTH CAROLINA**

### **Key Points**

- Studies conducted in North Carolina, Massachusetts, and Florida showing that Medicaid patients have cancer outcomes as poor as those of the totally uninsured reinforce the idea that insurance is necessary but not always sufficient to obtain appropriate screening and treatment. These findings appear to have important policy implications. Similar studies should be conducted in other States to determine if similar situations exist elsewhere. Dr. Harris reiterated that in her survey of Medicaid-eligible patients, many did not understand that Medicaid would pay for prevention/early detection services as well as services for active disease. This finding points to a need to educate the target population about the scope of Medicaid benefits. It also was noted, however, that Medicaid benefits for screening are quite limited.
- Advertisers are well aware that communication is a complicated psychological and social undertaking. To stimulate behavior and attitudinal changes, people must see themselves as part of a narrative.
- Barriers to cancer care access, such as transportation issues, may well have underlying sociologic bases (e.g., the distribution of dollars in a community, the structuring of poverty) whose illumination through research would be of value in understanding and eliminating the apparent barrier.
- Science can itself be the source of confusion among the public. Information about beneficial dietary and other lifestyle practices changes so rapidly that people do not know what to do. The effect is that information “undisseminates” itself.

### **Recommendations**

- NCI should consider an approach to cancer communication that is more multidisciplinary in nature. Sociology, anthropology, ethnography, and studies of group behavior and thought have much to contribute to the understanding of how best to disseminate information and why people do or do not choose to act upon information they receive.
- The NCI should do what it can to disseminate the stories of the survivors who have testified before the Panel. These narratives present the kind of information with which people can identify and are extremely effective in communicating cancer information.
- The Eastern Band Cherokee tribe resides primarily on the reservation described by Ms. Wiggins. In addition to the IHS hospital, a few tribal health care services are offered. The principal problem is that there are too few providers for the population.

### **CLOSING REMARKS—DR. HAROLD FREEMAN**

Dr. Freeman highlighted the day’s testimony and thanked the speakers for their participation and for providing valuable insight into the serious problems that people encounter in seeking cancer information and cancer care.

I certify that this summary of the President’s Cancer Panel meeting, *Improving Cancer Care For All: Real People—Real Problems; Why Don’t All Americans Get The Best Available Cancer Care?*, held November 16-17, 2000, is accurate and complete.

Certified by: Harold P. Freeman Date: 09/05/02

Harold P. Freeman, M.D.  
Chair  
President's Cancer Panel